

Bureaucratic Barriers to  
Normal Day-to-Day Activities

A Muscle Power! Report  
Written and Researched for Muscle Power!

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*@ Muscle Power! 2000*

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*Foreword by Jane Campbell, Disability Rights Commissioner, Co-Director of the National Centre for Independent Living and a member of Muscle Power!*

"Bureaucratic Barriers to Normal Day-to-Day Activities" is a report based on the *actual experience* of disabled people with neuromuscular impairments, telling it how it is for us today. The purpose in presenting it is to try to bring about change, and to break down some of those unnecessary "bureaucratic barriers".

Muscle Power! decided to focus on the barriers faced by those with neuromuscular impairments because that is our experience. However, the barriers we face are mirrored in the experiences of very many other disabled people.

As ever, this report has been produced on a shoestring. Funding was only available for actual production of the report -not for any of the research or writing that went into it. The Report has only been possible with the generous sponsorship of Equal Ability, a consultancy firm run by one of Muscle Power!'s members, and the investment of considerable time, gratis, by the authors.

Muscle Power! was keenly aware, whilst preparing this Report, of all our friends and colleagues with neuromuscular impairments who are no longer with us -members of Muscle Power! and others we have known. During their lives they experienced untold bureaucratic barriers. Their struggle to control their own lives in the face of such barriers has inspired us to try to change life for those who still live and those who will come after us. We dedicate this Report to their memory.

I would commend this Report to you as a document which should expand your understanding of the real lives of a significant number of disabled people. It highlights the additional and, we would argue, mainly unnecessary strain we, as disabled people, are put under and begins the debate on how barriers can be removed. We hope those with the power to remove those barriers will want to work with us to find ways of doing so.

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### *Information about obtaining this Report*

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## *A. Key Findings and Recommendations*

### 1. In General

1.1 The Report looks at key activities which most people take for granted as part of normal day-to-day life. For each "normal day- to-day activity" that the research looked at, issues were identified and then suggestions made that might begin to break down the barriers. Many of these relate to different agencies and these have been identified in section 0 of the Report. There are, however, some key themes that have emerged. The Report makes recommendations that different parts of the service delivery and quality assessment process will need, we believe, to address including:

- National Government, including Departments of Health, Social Security, Education and Employment, and Environment, Transport and the Regions

- National Agencies including NHS Executive, Social Service Inspectorate, Benefits Agency, Employment Service
- Disability Rights Commission
- Local Agencies: Commissioning
- Local Agencies: Service Delivery

1.2. The types of issues which need addressing include:

- national policy and strategy
- agency review and investigation
- local policy and procedure
- procedures and staffing issues for individuals

## 2. Findings

- 2.1 All those who responded had experience of bureaucratic barriers affecting their lives. The bureaucracy which surrounds the provision of services, or the funding of support for many disabled people, particularly those who need a high level of personal care, is significant, and in many instances unnecessary.
- 2.2 For everyone these barriers undoubtedly added to the difficulties already experienced living as a person with a neuromuscular impairment (NMI). The bureaucracy adds, unnecessarily to the difficulties we face living with our impairments in a society which still discriminates against us. For all those responding, their quality of life, freedom, and privacy as individuals, and their ability to achieve independent living, were adversely affected by the barriers. For many their ability to contribute to society was compromised. For some the ability to work was denied purely through "the system". For others their health and safety, and even their lives, were put at risk. This bureaucracy devalues us as individuals.
- 2.3 The Report makes a range of recommendations, which may not all be implemented -and certainly not all at once. Because the effects of the bureaucratic barriers is cumulative, removing just some of the barriers will make a significant difference to disabled people's ability to manage the others. Some recommendations would have a profound impact on barrier reduction, however, and should be treated as a priority. For instance, introducing the Personal Profile as recommended would remove a whole host of barriers at one fell swoop.
- 2.4 All agencies were found to erect barriers. Because of the level of personal care many people with NMI depend upon, the social care agencies were major players. However, there were a significant number of ways in which health

services added to people's problems unnecessarily. And barriers erected by the private sector were identified by a number of those responding.

- 2.5 Although the bureaucratisation is often money led, the level of professional input needed to maintain it is a significant drain on the overall resources available to support our needs. There is duplication of bureaucracy because we are not seen as a whole. If we receive funding for different needs or from different sources -e.g. ILF and DSS -each one tends to want to make its own checks on our use of their resources. One check on our use of resources, if one was necessary, could be shared.
- 2.6 Bureaucracy often appears to be used as a means of restricting our legitimate claim for services or support. We are given "hoops" to jump through which can confuse and exhaust us. Many people just do not have the energy and give up. For most people with NMI, "jumping through the hoops" poses additional stress and strain, risking health or even life. But the alternative of not obtaining essential services can have a similar effect. A stark choice.
- 2.7 Many bureaucratic rules are about minimising risk. However, in our experience they only mean a transference of risk, from the organisation or individual supplying a service or resource, to us as the disabled person. There are occasions on which we would want to be allowed to take risks, but we are prevented by the bureaucracy, but more often we have no choice but to assume risk if we want services or resources. Our needs seem to be left out of any assessment of risk. Blanket rules are imposed which are not flexible enough to include our legitimate needs and as a result we are put at risk. We are also required to sign waivers relating to risk in situations where, if it was not disability equipment or services, it would not be countenanced. Someone purchasing a sports car is not required to sign a waiver for the garage or the manufacturer despite the undoubted risk from improper use.

### 3. Recommendations

- 3.1 Strategies, policies, and procedures should be developed taking into account the specific needs of people with different impairments. Disabled people should be involved in such development.
- 3.2 Personal Care, essential to independent living, for a disabled person, should be free. This would, at a stroke, remove a very significant number of the barriers, and free people to achieve their maximum potential as individuals.
- 3.3 A Personal Profile should be developed, held by the individual but structured in such a way that individual agencies could access the information they needed -

and only that information. This would enable a once and for all assessment of an individual's need. It would, in the case of someone with NMI who is not going to miraculously improve, only need to be updated when an individual felt their condition had deteriorated to such an extent that they needed to be reassessed.

- 3.4 Direct Payments should be immediately available for all who wish to use them, with appropriate support available for the individual from their peers. Resources need to be provided for the latter.
- 3.5 Self-managed funding should be available for more than just personal care. Essential aids, equipment and support for independent living could be dealt with in this way. Access to Work could for example, be dealt with in this way.
- 3.6 There is an increasing understanding of the physical and attitudinal barriers which disabled people face. However, when it comes to bureaucratic barriers they are little acknowledged, let alone understood. The advent of the Disability Rights Commission (DRC) offers a real opportunity to bring these issues, many of which this research highlights, to the forefront. We hope that the DRC will take up a number of the recommendations suggested to review discrimination, inform service providers, and assist the removal of many bureaucratic and unnecessary barriers.
- 3.7 There needs to be greater clarity of rules relating to the provision of services and equipment and greater consistency in their enforcement. We understand the argument that less control from the centre means greater flexibility to meet individual needs, but it also leaves the way open for greater inflexibility. The rules from the centre need to be clear to everyone, providers and users, so people are clear about the framework within which they are negotiating. Disabled people must be involved in local variations, having been fully informed and resourced to contribute effectively.
- 3.8. Better advocacy provision needs to be developed to assist individuals to negotiate the system and ensure their needs are met. This will benefit not only the individual but also the agencies concerned.
- 3.9. The introduction of Best Value principles is a positive step for disabled people if they are correctly implemented. They should clearly enable agencies to take into account the benefits as well as the direct costs, of meeting all individual needs in the most empowering way.
- 3.10. Paying for essential assistance, for example when going to the cinema, should be recognised as a legitimate cost of independent living, in the same way that it

would be if a care home were organising a trip out. The resources for it need to come from independent living payments, not as charity from the cinema or other leisure venue.

- 3.11 All reviews of bureaucratic barriers should involve disabled people, properly resourced to represent the needs of people with the whole range of access needs and impairments.

## *B. Introduction*

### 1. Who is Muscle Power! ?

- 1.1. Muscle Power! is an organisation controlled and run by people with neuromuscular impairments (NMI). NMI covers a range of muscle wasting conditions. Often people with NMI are or become permanent wheelchair users, but also, many have difficulty walking distances, standing up, using their arms - gripping, reaching etc. -and some have difficulty speaking.
- 1.2. Many members of Muscle Power! are active in disability related areas, internationally and locally. They use their experience to assist other disabled people to improve their quality of life, by taking advantage of what is available. In addition, many members of Muscle Power! also work full or part-time.
- 1.3 The nature of NMI, and particularly the early onset. of many of the conditions, means that people often need a greater level of personal care, and require very individual manual handling techniques. Many may be prone to respiratory infections, especially if not given appropriate care. Most of the conditions are progressive and progression is aggravated by inappropriate care and by stress.

### 2. Our approach

- 2.1. This Report arose from the desire of Muscle Power! to use their experiences to inform the development of policy underlying the support structures for independent living. When discussing how they might mark the 10th Anniversary in 1999 and lay foundations for Muscle Power!'s next 10 years, the Management Committee decided to research and write a Report on the bureaucratic barriers faced by disabled people, and particularly those of us with neuromuscular impairments. The Report is based on the experiences of Muscle Power! members and other people with neuromuscular impairments. The intention is not to show problems faced solely by us, but to use our experiences -by definition those we know best -as a microcosm of those faced by all disabled people. By definition, the contributions are anecdotal -but they reflect our perceptions of independent living, and in this, as in so many areas of life,

perception is reality for us. Some of the contributions may also be out-of-date in their factual content, but we believe this highlights one of the major bureaucratic barriers -access to up-to-date information.

- 2.2. Contributions were gathered during the latter part of 1999. We invited responses from our members, and through our disability networks including the Jennifer Trust for SMA and the Muscular Dystrophy Group. We encouraged them in whatever format was easiest for the individual concerned and received them by e-mail, disk, letter, and 'phone. We also gathered responses at a Conference held in conjunction with our AGM in Derby on 11 September 1999.
- 2.3. Many people found it difficult to think of examples of bureaucratic barriers, as they are so used to working around the system that it has just become another part of life. Indeed, if people stopped to analyse what's happening every time they encounter such a barrier, their stress levels would become so great they could no longer function. As the contributor of Life Scene 4 says "I am sure there are many other situations I could think of but my blood pressure is getting too high, thinking about it all!". Few people are able or would wish to analyse their situation in the way that the academic who contributed Life Scene 2 has done. Consequently, a number of valuable examples came to light through conversations with members and others. Written contributions are included in the Report as an appendix, entitled Life Scenes. The others have informed the main body of the report, but have not been recorded separately.
- 2.4. One of the life scenes has been written posthumously by a friend who acted as informal advocate. The person concerned spent over a year struggling against bureaucratic barriers erected by social services in order to provide his basic personal care. The stress of the situation laid him open to infection, and he contracted pneumonia. He was taken into hospital where, having again to struggle with bureaucratic barriers -this time put up by the health service -whilst in a weakened state, he gave up the unequal struggle and died. He had given permission for his experience to be included, and we know that he would welcome the final chapter of his story adding its weight to this Report.
- 2.5. His experience has brought into sharp focus for us the need for this Report and steeled our resolve to ensure it is an effective contribution to positive change in the independent living arena. As Rachel Hurst says, in her Forward! to HCIL's 1986 Source Book Towards Independent Living "The problems of daily living must be solved for disabled people, as there is no margin for error. .
- 2.6. Mindful of the Disability Discrimination Act 1995 (DDA) and its definition of disability, we have taken the concept of 'normal day-to-day activities' as the basis of our Report. However, the definition of 'normal day-to-day activities' in

the DDA is about an individual's functionality -whether we can stand, concentrate, carry things, are continent and so on. When we think about 'normal day-to-day activities' we think more about activities 'normal' people engage in from day-to-day -such as getting up and dressed, going to work, going on holiday, going to the toilet and so on. It is this latter approach that we have adopted in writing this Report.

- 2.7. We recognise that going to school and to college is also a 'normal day-to-day activity'. However, most of the contributors to the Report were educated some time ago, and we do not feel that our experiences of segregated or mainstream education can add much to the existing picture. We welcome, however, the news that the right to mainstream education is to be brought within the framework of the DDA.

### 3. Bureaucratic barriers

- 3.1. In the traditional view, disability is seen as the result of an impairment or a medical condition particular to the individual -a 'problem' within the disabled person because they are not 'normal'. Because of 'their disability' (the impairment or medical condition) disabled people cannot do the things they want to do. We have to be 'cured' or 'fixed' so we can be 'normal' (or as normal as possible) and thereby play a limited part in society. This has been termed the Medical Model of Disability.
- 3.2. Since the beginning of the 1980s, disabled people have developed their own understanding of the barriers that they face in life. This understanding, called the Social Model of Disability, is increasingly accepted as the equality approach and a significant number of organisations are now trying to look at their employment and service practice in the light of this Model.
- 3.3. The Social Model shows that what really disables people are the barriers society creates by failing to take into account the wants, needs and aspirations of a significant portion of the population. To 'cure' disability it is society that needs to be 'fixed' -its attitudes, organisation and physical structures. Changes are seen to be beneficial to all. Equality for disabled people is seen in the same light as equality for other groups which experience discrimination, and personal experience of disability may be viewed as a positive asset.
- 3.4. Quite a lot has been written and researched about physical and environmental barriers to disabled people's ability to play a full part in society. These barriers range from the obvious flights of steps, to the more subtle lack of information about which route to follow -which can add unnecessary distance to a journey and cause physical fatigue. 'Bureaucratic barriers', on the other hand, can make

the difference between policies, practices and procedures that enable, and those that disempower. But even positive policies and procedures can create bureaucratic barriers if they are applied legalistically by someone with an unhelpful attitude.

- 3.5. Muscle Power! members are acutely aware, from personal experience, that the way in which "the system" works -the way things have to be done, or people think they do -has become an increasing barrier to our independence. These 'bureaucratic barriers' have barely begun to be explored or discussed, and yet affect our day-to-day lives in ways that non-disabled people don't even have to think about.
- 3.6. Almost everyone faces times when they feel "the System" is against them. For disabled people, contending with everyday life is hard enough. How much more frustrating when organisations supposed to provide the basic support and assistance do it in such a way as to make it significantly more difficult than it needs to be to access or maintain that support and assistance. It has been described as "running to stand still" (Phil Mason, HCIL).
- 3.7. Bureaucratic barriers are the result of rigid bureaucratic structures that require a person to fit the structure rather than vice versa. But people are different, and no two people will fit neatly into the same structure. Bureaucratic barriers are usually intangible. For example, when two agencies quarrel about funding for personal care or basic equipment, we as disabled people are 'piggy in the middle', and do not get the support we need while they battle it -.Out. Or, perhaps, the responsible agency is clear and agreed, but we must fulfil specific criteria to get the support, and our lives don't fit neatly into the right pigeon holes. No two agencies seem to have the same processes, the same criteria, the same forms to fill out, even!
- 3.8. But the essence of bureaucratic barriers is that they are not, in general, difficult or costly to break down -they are essentially about changing practices, policies and procedures -a fundamental part of non-discrimination supported by the Disability Discrimination Act 1995. Breaking down bureaucratic barriers is about making the individual the focus of the process, rather than the organisation or agency.
- 3.9. One of those responding started their contribution by saying:

*I think this project is an excellent & long overdue idea & congratulate Muscle Power! for doing it. In reply to your opening question of "Are there times when you feel 'the system' is against you?" I would say, almost always because it is! Although increasing numbers of 'right on'*

*organisations adopt sensible language & talk of adopting an holistic approach, unfortunately the reality is very different.*

#### 4. Independent Living

- 4.1. Independent living is about taking control of our own lives. It is about making our own choices: when do we get up in the morning? what clothes do we wear? what will we eat for dinner? who do we go to bed with? Many non-disabled people feel that they do not have control over their own lives -they must get up at a certain time in order to catch the train in order to get to work - but they can at any stage change what they do, albeit with significant consequences to their lifestyle and financial position. Disabled people who need personal care cannot change their lives unless they have that basic support available as and when they need it.
- 4.2. Improving disability services (Living Options Partnership Paper 3) says:  
  
"For disabled people to live and participate fully in community life it is essential to have services which enable them to do everyday tasks, such as getting up, dressing, eating and childcare.
- 4.3. "'Independent living' is a term that disabled people use to describe the support they require in order to live in the community. It is a concept which stresses the importance of disabled people retaining maximum control over their own life.
- 4.4. "'Independent living' usually refers to a situation where disabled people either directly employ personal assistants, or go through some form of agency to obtain personal assistants."
- 4.5. Disabled people and their organisations have defined the seven needs of independent living, without which we cannot have true choice over our lives. These are: access, information, transport, assistance, housing, peer support, and aids & adaptations. These needs are reflected in the contributions to this Report.
- 4.6. If disabled people cannot control the basic 'normal day-to-day activities', we have little if any hope of controlling any other aspects of our lives. For instance, daily life starts with getting out of bed, and much of what we do thereafter is dependent on controlling when we do it. We cannot make arrangements to meet friends, or for the gas man to call; we cannot go to work; we cannot get out to the mobile library which only comes once a week at a specified time. And how would we get the children to school on time?

## 5. The aim and intended audience of this Report

- 5.1. We intend this Report to contribute to improving the quality of life, not only of people with NMI but of all disabled people.
- 5.2. We hope those who read this Report will discover the human effect of bureaucracy first-hand and will take very seriously our suggested solutions and recommendations.
- 5.3. Those who frame national policy and strategy can, we believe, learn from this report. There is much that can be achieved in breaking down unnecessary barriers through appropriate, more joined-up, thinking and service planning.
- 5.4. Those who write local policies and procedures can also learn from what we have found. They have the opportunity to facilitate a vastly improved quality of life for very many disabled people.
- 5.5. Those who work in the services we use can also learn from this report. The Report "tells it like it is" for those of us with NMI. We hope they will read and understand, to enable them to support us better in living independently.
- 5.6. Finally we hope students who will become the policy makers and -managers of the future will also read this and learn of the reality of lives blocked by bureaucratic barriers.

## c. Normal Day-to-Day Activities

### 1. Just Living!

#### 1.1 *Acknowledging the issues*

- 1.1.1 Most non-disabled people do not even consider the process they go through in getting out of bed, getting dressed, washing, eating, going to bed -and even breathing! These are, however, 'normal day-to-day activities' for everyone, and a vital foundation for the rest of life.
- 1.1.2 For most people with NMI, these activities are things we are forced to think about and plan for all the time. Life is therefore much more complex than for most non-disabled people. Juggling care needs within a resource package which seldom meets them fully, and often on limited strength and personal resources can be an extremely onerous burden.

- 1.1.3 Some of the most basic bodily functions such as going to the loo and coughing are adversely affected by bureaucratic rules. These are mentioned in more detail later in the Report (C2, CB).

#### *Managing our personal assistance*

- 1.1.4 Sometimes, we are forced to limit the extent to which our basic needs are met, because we do not have the resources to pay for them. The contributor of Life Scene 7 says: "I cut back on the hours of assistance and really only use my PAs for the real necessities. It is however quite a struggle, but it's better than nothing."
- 1.1.5 Educating those who provide personal care can be a long process for those of us who need intimate and particular care. When the system allows those in control to change rotas and reallocate staff, the whole process must be repeated. This can affect the length of time things take, and therefore the amount of support needed. One contributor mentioned that with a new P A, getting up took an hour or more. Whereas with an 'old hand' not only could it take as little as half an hour, but the personal interaction and concentration required over that period was significantly reduced, leaving more energy for other activities.

#### *Fitting into the system*

- 1.1.6 When we have secured a service which we may only require from time to time, we can lose it and have to go through all the hoops of a fresh application because the system cannot cope with an intermittent need. The contributor of Life Scene 5 mentions 'losing' occupational therapy support when it was not needed for a six month period. Another contributor stopped swimming for 6 months due to a non-impairment related illness and found that their right to a swimming place had been lost.
- 1.1.7 One contributor (Life Scene 10) was required to differentiate between the care that she needed for 'domestic' purposes and her 'personal' care. This is a distinction that non-disabled people would not even consider -let alone be able to achieve. It is also highly subjective, and variable -when does laundry become 'personal' as opposed to 'domestic'? When your dirty clothes get up and walk out on their own?!
- 1.1.8 Household tasks such as cooking, cleaning and laundry may be possible, but may use up valuable and very limited stocks of energy. For a person with NMI, it is often a choice between cooking a meal or ironing a shirt. Yet the systems of assessing care within which we work do not recognise the cumulative effect of activities on a person's reserves of strength. A legalistic assessment could

require a person carrying out a significant number of household tasks which, technically, they could undertake. However, the fact that to carry out these tasks would take the whole of their energy allocation for the day and allow nothing for paid work or even leisure, is in danger of being ignored.

- 1.1.9 Many responding had care packages which led to them "living on the edge". The funding allocated allowed for their needs to be met when they were well, and often when they were able to go to work where other arrangements kicked in. However, if for some reason they are unable to get to work, or are poorly and need a higher level of support to stay in bed or just survive, there was nothing in the budget.
- 1.1.10 But even those of us who receive support for household tasks may be prevented from using that support to achieve the end that a non-disabled person would do, due to bureaucratic barriers. The contributor of Life Scene 4 mentions not being able to get her curtains washed or her children's rooms cleaned because of bureaucratic rules.

### *Housing and equipment*

- 1.1.11 Many people with NMI depend on a range of equipment for living. This may be electric hoists for bed or bath, electric wheelchairs to get around or a lifflor get downstairs. When bureaucracy requires authorisation to be obtained before vital equipment can be repaired, we have to make do without the equipment -which may mean staying in bed for a few days. The contributor of Life Scene 4 illustrates this well.
- 1.1.12 Sometimes we can work out solutions which work for us. Unfortunately, if they do not fit in to the bureaucratic system we can run into problems, as the contributor of Life Scene 14 shows. Sometimes we get so frustrated that we use limited resources to buy essential equipment, for instance an electric wheelchair. One contributor told of being refused fitting of NHS arm supports on a replacement wheelchair which had been bought with private funds. If we buy equipment which could be financed through public funding, the maintenance of that equipment is something we generally also lose out on.
- 1.1.13 The place where you live is an important factor in quality of life. Finding accessible accommodation, particularly if you are a wheelchair user, is difficult enough. When grants to assist in making houses more accessible are not available unless you are already living in the property, bureaucracy prevents many disabled people moving at all -as the contributor of Life Scene 4 points out. Even when you are living in the property for which you need a grant, "it is

quite a minefield", and not a speedy process, as the contributor to Life Scene 6 explains.

- 1.1.14 Getting any adaptations or equipment may be fraught with form filling and assessments. One contributor applied for a grant for environmental controls which he knew would meet his need. Three organisations (but not the individual) funded the package. It took 5 people to assess him -at great cost to the statutory authorities. When things did not work, and progress was not being made by the suppliers, no one knew whose responsibility it was. "I want to know where the buck stops and who says jump" he told us.
- 1.1.15 If you are renting, and want to take advantage of the Right to Buy or a Tenants' Incentive Scheme you may not be able to. One contributor explained that if they wanted to take the money from a Tenants' Incentive Scheme, they had to move out immediately, but adaptations needed to be done on the new property before they could move in. And the Right to Buy is not available if you live in a sheltered complex.
- 1.1.16 Care packages are not generally portable, and local authorities will wish to reassess the needs of someone moving into their area -and onto their budget - before agreeing to fund their package.

### *When it goes wrong*

- 1.1.17 When things go wrong, often the only route available to sort things out is to make a formal complaint. As the contributors of Life Scenes 4 and 10 point out, this is a long and stressful process, and often unsatisfactory for everyone involved.

## *1.2 Solving the problems*

- 1.2.1 Ensure disabled people have as much choice and control over our lives as possible.
- 1.2.2 Develop, in partnership with disabled people, a greater understanding of what comprises quality of life, and how disabled people add value to society.
- 1.2.3 Establish beyond question that basic personal care is a right and should not have to be funded from an individual's own purse. Medical interventions are accepted as essential, even if they are only about improving quality of life rather than maintaining life. They are considered a much higher priority -most people would demand free hip replacements under the NHS, but cannot fund their care where a hip replacement would not be effective.

- 1.2.4 Develop, with disabled people, a new and creative approach to establishing people's need for support and equipment. Very many people, including those with NMI, have conditions which are not going to improve. A 'Personal Profile', held by the individual, could be used as a 'passport' to personal care and equipment. This would enable a once and for all assessment of an individual's need, which would only need to be updated when an individual felt their condition had deteriorated to such an extent that they needed to be reassessed. This would streamline the assessment process, and justification of needs using the Profile should lead immediately to acceptance. Significant resources will be saved in duplicated assessments and the maintenance of bureaucracy.
- 1.2.5 The Personal Profile should remove the need for the Benefits Agency and others to review many disabled people's right to benefits. This would provide an approach linked to an individual, rather than the blanket exemption provided, for instance, for Benefits Integrity Project (BIP).
- 1.2.6 Ensure that the option of direct payments is available to all who want it. Many local authorities still have not introduced them.
- 1.2.7 Recognise the adverse effect on health of a minimalist approach to needs assessment. The additional strain of trying to cope with insufficient support can have an extremely negative effect on health which is probably not "cost effective" for the Treasury.
- 1.2.8 Ensure all people's independent living care needs are funded so people are not forced to "live on the edge".
- 1.2.9 Abolish the domestic/personal care divide, and re-focus on needs for independent living.
- 1.2.10 Facilitate the acquisition of housing by changing the rules relating to the Disabled Facilities Grant. It should provide greater flexibility, more simply, and be purely needs related -not means tested. A Personal Profile would contribute significantly to this simplification.
- 1.2.11 Develop a clear agreement between agencies on what constitutes 'personal' care, with flexibility for people with different impairments -for instance those requiring more laundry.
- 1.2.12 Provide an emergency repair allowance for vital equipment. Adopt an 'innocent until proven guilty' approach to repairing vital equipment -get it fixed, and then decide whose responsibility it is to pay.

- 1.2.13 Provide more flexibility -a bigger "buffer" -in care packages to cover fluctuations in an individual's condition, or illness.
- 1.2.14 Encourage a good "out of hours" service provision by care agencies and those supplying equipment, to cover failure of support arrangements and of vital equipment.
- 1.2.15 Notify a disabled person when the agency proposes to terminate a service that has not been used for some time.
- 1.2.16 Ensure more joined-up funding, and a clear indication when more than one agency is involved of who exactly it is that says 'jump'.
- 1.2.17 Develop a national standard of service entitlement and supply.
- 1.2.18 Through national policy, nurture a partnership approach between statutory agencies, and those they fund, including disabled people.
- 1.2.19 Develop a less confrontational way of taking action when the system fails to meet our needs.

## 2. .... and going to the loo .....

### 2.1 *Acknowledging the issues*

- 2.1.1 In general, non-disabled people do not consider how or when they go to the 100 at all. It's only at unusual events, such as a rock concert, or the Millennium celebrations on the banks of the Thames that they have to take this very basic function into account. Because this is such an important function, we have chosen to single it out, rather than include it in *Just Living!*

### *Getting the timing right*

- 2.1.2 For many people with NMI, going to the 100 is a long process. The contributor of Life Scene 3 writes that it can take her half an hour, but Social Services could only offer a 10 minute 'pop-in' service. Another contributor, who also takes half an hour, often has to build this into a busy schedule of meetings, and is frustrated by colleagues who design meetings according to a very strict timetable and are not prepared to be flexible.

## *Health and Safety*

- 2.1.3 Many people with NMI have particular requirements when it comes to being moved. These are not just personal preferences -they can affect their safety, or their health. Health and safety of staff is seen as important, whereas health and safety of the disabled person is not considered, as the contributor of Life Scene 8 highlights.
- 2.1.4 Actually working within the confines of the care available can have a very adverse effect on an individual's health. A significant number of contributors limited their liquid intake, or waited much longer than was good for them, in order to avoid trips to the 100. One contributor who was on the borderline of ILF funding chose not to have care during the day for trips to the 100, rather than go over the limit of local authority funding and get into another means tested process which she knew would have an adverse financial implication. For overnight trips to the 100, the system only allowed a half hour call-out at £2.50, out of which the personal care assistant would have to fund their travel costs.

## *When it goes wrong*

- 2.1.5 It has already been noted that most care arrangements are not flexible enough to cater for the out-of-the-ordinary -such as a stomach upset or particularly heavy period.

## *2.2 Solving the problems*

- 2.2.1 Acknowledge the fact that to go to the 100 is not a privilege. It is part of the basic personal care which an individual should not have to fund out of their own resources.
- 2.2.2 Introduce greater flexibility into care packages -such as timing and who can provide care.
- 2.2.3 Train and encourage care staff to be honest about their level of knowledge of impairment. Staff are not expected to know everything, and should be able to accept instruction from the disabled person.
- 2.2.4 Install unisex accessible toilets rather than -or as well as - segregated provision. This will assist those whose personal care assistant or partner is of the other sex.
- 2.2.5 Review and ensure better Health and Safety training which encourages a less generic approach that can be tailored to individual situations.

### 3. Getting Out and About

#### 3.1 Acknowledging the issues

3.1.1 Every day, non-disabled people leave their houses on foot or by car, in order to perform necessary tasks such as going to work, shopping and taking the children to school. Except when the bus or train doesn't turn up, the car battery is flat, or there is an unexpected traffic jam, people give little thought to their regular travel arrangements. And when something does go wrong, most people have another option -a friend's car, public transport, walking. It's only if someone, for example, sprains an ankle, that they are prevented from getting out and about.

#### *Getting and using a wheelchair*

3.1.2 Many people with NMI cannot leave their houses without support. That might be human support or specific equipment, or both. For those who need an electric wheelchair, there is now some NHS funding available. But the eligibility criteria are not universal. So in some areas, in order to qualify for what is effectively the ability to walk to your corner shop, you must pass an eye sight test like the driving test. If you have private means, you do not have to pass such a test. The limit on available funding is especially difficult for many people with NMI who need more than just the basic wheelchair. Sometimes the chair that meets their needs will not be available from an authorised distributor, or be approved by the Medical Devices Agency, and they will not be able to have it. Once you have got a wheelchair, the rules you are expected to obey, in relation to use, can limit your freedom, like the rules about when a chair may be used on the road.

3.1.3 Because wheelchairs are such a fundamental mobility aid - without which people may not even be able to get out of bed, let alone out of the house -it is important for people to have immediate access to a replacement. Wheelchairs are not cheap, and many people cannot afford to buy their own. The rules governing the issue of wheelchairs prohibit the provision of two chairs to one person as the contributor of Life Scene 4 mentions. Even those of us who are able to afford to buy our own chairs are then obliged to maintain them ourselves -which can itself be prohibitively expensive.

3.1.4 The voucher system for wheelchairs is of some use in buying wheelchairs. However there is a distinct lack of clarity amongst wheelchair providers about the availability of vouchers for electric wheelchairs. Availability varies from

district to district -and two of our contributors found variation within one district.

### *Using public transport*

- 3.1.5 It is well known that public transport is not the most accessible. However, even when it is accessible, the rules governing its use by disabled people -and particularly wheelchair users -put up unnecessary barriers. In general, train journeys must be booked in advance. Hours of opening for the phone lines to book a journey differ from one company to another, and to book is therefore not easy. When the seats are all taken on a train, non-disabled people can choose to stand, or take the next available train. Wheelchair users cannot guarantee that they will be allowed to sit in the corridor of the train -and they certainly cannot book assistance if they plan to do this.
- 3.1.6 Public transport is timetabled. If someone's care package does not enable them to get ready in time to catch a particular bus or train, they may not be able to get to work, or attend a health care appointment.
- 3.1.7 Planning a journey by public transport may be difficult enough for non-disabled people. For disabled people, information about access is often not available in the mainstream, and may have to be acquired from a head office only open during office hours. Even then, for means of transport such as trains and buses, companies are reluctant to provide information about access because they may have to switch (rolling) stock at short notice. Many disabled people would be happy to take this risk, but are not given the choice. One contributor had to find out from the hotel she was staying in whether the local buses were accessible as the operator would not provide the information.
- 3.1.8 The rules about concessions and accessibility are often so complex that staff are not aware of them. Disabled people can miss out on provision that they badly need because they are given wrong information. In order to get the maximum concession for having to travel in the guard's van of a train, the wheelchair user must get the guard to sign the back of their ticket. They can then send *the* ticket to the train company and receive a rebate. One contributor was aware of this, but the guard was not and refused to sign her ticket. He offered to arrange for her to see someone at the station, but she had a business meeting to attend and did not have the time. As she commented 'What illicit activity could I have undertaken with the guard's signature on the back of my rail ticket?'

### *Using door-to-door transport*

3.1.9 Where 'special' tailored transport is provided, such as Dial-a-Ride, the rules governing its use can be very restricting. For example, people may not be able to travel with friends or relatives if they are not 'essential escorts'. The contributor of Life Scene 3 highlights the problems of travelling out of the local area, and the impact that can have on daily activities.

### *Using a private car*

3.1.10 When it comes to owning and driving private vehicles, the barriers do not seem fewer. Many people with NMI require significant adaptations to their vehicles. If they drive they may need to do so remaining in their chair. Even if they do not drive themselves they may need a vehicle which allows them to remain in their chair. Some funding is available, mainly through Motability, but many people are forced to top up this funding with donations from relatives or charities. Rules about accumulating capital whilst on benefit, or receiving funding for personal care, have been a major barrier to disabled people's ability to buy and maintain vehicles. Where the adaptations may cost more than the vehicle itself, rules about replacing vehicles of a certain age can prohibit access to funding.

3.1.11 For those of us with NMI who cannot use other forms of transport, but who lead lives which are active and full, the mileage restrictions in the Motability scheme can be a significant barrier to our quality of life. Similarly the requirement of a vehicle being returned when it is replaced under the scheme in a certain condition provides many with an additional barrier.

3.1.12 Vehicle conversions may affect the manufacturer's warranty. Disabled people's rights to claim for faulty workmanship can therefore be avoided by unscrupulous dealers purely because additional work has been done on the vehicle to meet the individual's needs -even where this does not affect the part at fault.

3.1.13 The assessment and funding process through Motability for a vehicle requiring significant adaptation is lengthy. One contributor told of a friend who had been assessed, but it took two years for their application to come through the system. By this time the adaptations made did not meet their needs and they were unable to drive it.

3.1.14 Often there is no choice of which supplier is used -the recipient of funding must go to the "approved dealer". This can prevent people getting the most appropriate arrangement for them in their particular circumstances.

- 3.1.15 Many insurance companies require details of the medical condition of the passenger of a vehicle who does not drive. This is unreasonable and unnecessary and also an undue intrusion into people's privacy. It can also impact on the premium. Although this may be illegal under the Disability Discrimination Act, it is additional hassle and stress to take action and it has an adverse effect on relations with insurers.
- 3.1.16 And once out on the road, finding a parking place can be a challenge. Many larger cities have their own variations of the orange (now blue) badge parking schemes, with time limits or other restrictions. One contributor on a business trip in an unfamiliar city, received a parking ticket because there was a time limit on all orange badge spaces, but she had no way of knowing this when parking up. Had she just parked the other side of the road in a standard meter bay, she could have parked indefinitely for free -but again, she had no way of knowing.

## 3.2 *Solving the problems*

- 3.2.1 Review the rules for wheelchair provision -making different rules for different circumstance if necessary. In particular, the rules for permanent wheelchair users need a different approach.
- 3.2.2 Extend the voucher scheme to the provision of electric wheelchairs.
- 3.2.3 Encourage, and if necessary regulate for, increased consistency in customer service provision by public transport operators.
- 3.2.4 Establish a single point of contact for disabled people to gain information about and book accessible public transport. This could begin with an individual transport mode, and then extend to different forms of public transport.
- 3.2.5 Allow disabled people information so that they can decide whether to take risks for themselves.
- 3.2.6 Establish, with disabled people, ways of providing information on changes in provision -for instance late changes in rolling stock - that will enable disabled people to choose their own level of risk.
- 3.2.7 Review the rules governing disabled people's use of public transport, for instance rules imposed by train operators.
- 3.2.8 Review the situation surrounding alterations and adaptations to vehicles, in particular their effect on warranties.

- 3.2.9 Introduce consistency of orange/blue badge rules across the UK, with clear information at site.
- 3.2.10 Thoroughly review the Motability Scheme and remove the unwarranted barriers it presents to certain disabled people - including excessive timescales -in achieving the greatest level of mobility possible for them.
- 3.2.11 Review the capital rules within the benefits system affecting the accumulation of capital for the purchase and maintenance of essential equipment, including vehicles, by disabled people.
- 3.2.12 Investigate the provision of motor insurance cover for disabled people, and encourage good practice in that area.
- 3.2.13 Investigate and encourage the removal of artificial limitations placed on segregated systems of transport by bureaucratic rules.

## 4 Building personal relationships

### 4.1 *Acknowledging the issues*

- 4.1.2 Non-disabled people expect to be able to build relationships with people of their choosing. These may be social -friends, neighbours, work colleagues -or family -a partner, or even children! For people with a high personal care need, such as people with NMI, there are many issues to consider and barriers to overcome.

#### *It's all in the timing*

- 4.1.3 Inflexibility of personal care arrangements can have an adverse effect on social activities. As the contributor of Life Scene 5 points out, going to bed at 7pm as a twenty something year old is unacceptable.

#### *Playing gooseberry*

- 4.1.4 When someone relies, to any significant extent, on others for personal care, whether paid or unpaid, the presence of a third party in the social situation can act as an inhibitor. If the availability of care is limited, and the person is expected to rely on a family member, flexibility and privacy are compromised. Taking your mother on a hot date is probably not something most people would choose to do! Even with a non-family personal care assistant, rules about what they can refuse to assist with, or are not allowed to do, can limit social

activities. This might be something as intimate as helping someone use a vibrator or apply a condom.

- 4.1.5 Very many disabled people are not given appropriate sex education. Mainstream education and support groups have little if any real knowledge of the possibilities for people with NMI. Parents often have very low expectations for their children in this area or indeed, actively discourage it. Peer support in this area can be a vital way of breaking down this barrier.

#### *A burden on the family ...?*

- 4.1.6 Financial assessment-for an individual's personal care impacts upon the cohabiting partner. Not only are they almost certainly --contributing in kind to personal care, but they are also expected - if working -to contribute financially. This can add significantly to the strains of a relationship, and may be the cause of break up.  
Ironically, this results in a greater need for care funded out of the public purse when the partner moves out.
- 4.1.7 When care provision breaks down, the impact is not only on the individual, but on family members too. There tends to be an expectation that they should step into the breach. The contributor of Life Scene 8 was one such partner and his contribution highlights the effect of disruption on his working life.
- 4.1.8 When it comes to disabled parents, or carers, rules about what is seen as care for the individual can have a significant impact. The contributor of Life Scene 4 was unable to get assistance to clean her children's bedrooms once they reached the age of 9. Few teenagers keep their rooms clean or tidy, and in the worst case, not to have this support could be a health hazard!

#### *Going out on the town*

- 4.1.9 In venues for entertainment and leisure, policies about numbers of disabled people, seating arrangements and escort requirements can affect whether disabled people can build relationships with whom they choose. People with NMI are likely to have friends and relations who are wheelchair users. As one contributor found some venues have an arbitrary limit on the number of wheelchair users allowed in the building at one time, even when allocated seating is not at issue. Booking functions such as wedding receptions can be frustrated by these rules. Where allocated seating *is* at issue, most policies prevent people sitting with whom they choose -especially if both partners are wheelchair users.

## 4.2 *Solving the problems*

- 4.2.1 Ensure that informal carers or relations are not considered as a 'free' resource when assessing care needs.
- 4.2.2 Where social services can't provide appropriate personal care, let disabled people buy it in.
- 4.2.3 Clarify rules and encourage openness about why the rules exist.
- 4.2.4 Provide better sex education, information and guidance for disabled people of all ages.
- 4.2.5 Introduce better support for disabled parents. Take the parenting needs of disabled parents into account in the assessment of need
- 4.2.6 Fund a network of peer support for disabled people in personal relationships.
- 4.2.7 Provide training for personal care assistants to enable them to appreciate the sexuality of disabled people.
- 4.2.8 Ensure that as long as a personal care assistant is aware what is expected and signs up to it, they can do it -i.e. they are not barred by rules other than the law.
- 4.2.9 Recognise the right of people with NMI to a social life -not just the provision of services to maintain basic existence.
- 4.2.10 Remove arbitrary rules about venues -and ensure that necessary rules are clear and openly available
- 4.2.11 Make planning rules more flexible to encourage developers to provide creative, inclusive solutions, and to understand the benefits to themselves of *not* taking a minimalist approach.

## 5 Going Shopping

### 5.1 *Acknowledging the issues*

- 5.1.1 Many people are organised about their food shopping. However, it is not critical for them to be so, because if necessary, they can just pop out to the shop for a pint of milk or whatever. And other shopping -clothes, gifts etc. -can be done at

leisure, whether in a lunch hour, on Saturdays, or all in one go having saved up specially.

### *Let us pay ....*

- 5.1.2 Because of the rules on savings limits in relation to benefits or payments for personal care, disabled people may not be able to save up for a shopping spree for fear of going over the limit on savings. The contributor of Life Scene 1 had to prove that she had not frittered away what was actually her birthday money.
- 5.1.3 Getting the cash to go shopping can be difficult. Many A TMs are not accessible, and we cannot get the cash out ourselves. But telling someone else - a personal care assistant for instance -our PIN number is not permitted, and the bank can take a cash card away if we do so.
- 5.1.4 Where shops have credit card swipe machines that are inaccessible, many will tear off the slip before verifying the signature, so that a wheelchair user can sign at their own level. But some will not, citing credit card company 'rules' -a bureaucratic barrier that prevents us paying for goods as we choose -or perhaps buying them at all.
- 5.1.5 One contributor has her supermarket shopping done by her personal care assistant. She wanted to open an account at the supermarket, which she was prepared to fund up front, so that she didn't have to give her personal care assistant a lot of cash each week. The supermarket -a large chain -was unwilling even to consider this.

### *Try before you buy*

- 5.1.6 Where we buy clothes, we may be unable to try them on in the shop. Many shops have a flexible returns policy I but some have a time restriction -or a policy of no returns unless goods are faulty. For people with NMI who may have made substantial arrangements to go shopping, and may not be able to get back to the shop within the time specified, this can be very restrictive.

### *Coffee -and a sticky bun?*

- 5.1.7 And who, when they are out shopping, does not want to stop for a coffee or a snack? Where cafes have policies of requiring people to eat as well as drink at certain times of the day, personal care assistant users need to ensure that they can feed their personal care assistant as well as themselves.

### *5.2 Solving the problems*

- 5.2.1 Allow a disabled person to share their PIN with a named individual who can get cash out for them.
- 5.2.2 Provide cash account facilities at shops for a disabled person's representative to make purchases.
- 5.2.3 Ensure consistency and transparency of swipe card rules and machine design.
- 5.2.4 Establish the concept of 'registered personal care assistant user' for those who must have personal care assistance. This could be included in the Personal Profile, and should trigger the inclusion of the personal care assistant under the DDA provisions.
- 5.2.5 Review the capital rules within the benefits system which affect the accumulation of capital by disabled people. For people who, for reasons of impairment, live on benefit, the capital limits are very restrictive.
- 5.2.6 Increase the awareness of the retail sector to the bureaucratic barriers their policies present to disabled people.

## 6 Going Away

### 6.1 *Acknowledging the issues*

- 6.1.1 A non-disabled person will expect to be able to go away virtually when they please. Of course there will be limitations imposed by school holidays for those with children, or by work schedules. But whether it's a weekend away with friends or a holiday abroad, as long as the finances will allow, non-disabled people will be able to take advantage.

### *Making arrangements*

- 6.1.2 For people with NMI in particular, the arrangements required for going away are significant, and can prohibit even a well-planned holiday. Taking vital equipment, making arrangements for access during travelling, or at the place itself can be tortuous and the effectiveness of these arrangements is often unreliable.
- 6.1.3 One member wanted to borrow a hoist locally when away from home. The equipment was available, he used similar equipment at home, and he was entirely clear about his needs. Even so, he was told that to borrow it he would need to have a local Occupational Therapist assess him.

6.1.4 The need to book assistance for rail or air travel in advance removes the ability to be spontaneous, or take advantage of last minute offers. As the contributor of Life Scene 4 points out, she doesn't take any notice of the many advertisements and offers for holidays and so on, since she can be sure that they will not apply to her.

### *Flying high*

6.1.5 Air travel is especially difficult. Many airlines require medical clearance, which can take time. Even if someone has a frequent flyer clearance with one airline, this may not be valid on another.

6.1.6 Then there are many rules about where we must wait at the airport, whether we can keep our own wheelchair whilst we are waiting to board, where we may not sit on the aeroplane, and whether the airline can take our equipment - for example batteries for electric wheelchairs.

6.1.7 One contributor, a permanent wheelchair user needing to travel for business, told of flying with a carrier whose rules insisted she was lifted into the window seat. The rules also say that a disabled person cannot sit in one of the rows with no seats in front. So she had to be lifted by two airport staff across two seats between two rows. She had serious concerns about the health and safety of those moving her who did not seem appropriately trained, and were unable to lift appropriately whilst leaning over the seat backs -never mind her own personal safety and comfort.

6.1.8 Many staff are ignorant of the needs of wheelchair users and of wheelchairs. They do not understand the difference between one type of wheelchair or battery and another. The contributor of Life Scene 4 comments on these rules and regulations.

### *..... and lying low*

6.1.9 Hoteliers and travel agents do not seem to understand the need for access. There is often small print that allows them to ignore agreements made for particular types of room -e.g. a twin room, or an adjoining room for a personal care assistant. This can be disastrous for a person who needs to be in constant contact with their personal care assistant. And some people with NMI have very complicated routines when getting up in the morning, and may need to have breakfast brought to their room. Hotels that do not provide room service may not permit this -here the lack of permission forms the barrier, as we are likely to have personal care assistants who can go and collect the breakfast, so that the staff need not be involved.

6.1.10 One contributor told us of her honeymoon which was nearly cancelled. Travel operators would not guarantee that a wheelchair accessible bedroom would be allocated to her and her new husband. They could have travelled all the way out to Greece only to discover there was no accessible room. It was only a phone call to the company's managing director that secured an agreement to confirm arrangements just one week before the wedding.

### *Kids go free -but personal care assistants don't*

6.1.11 If a person does not have 24 hour personal care assistant cover, taking a personal care assistant away on holiday can be expensive. There is no allowance made for additional time required when we go away and take our personal care assistant with us -effectively increasing our care cover to 24 hours. The contributor of Life Scene 5 talks about this problem. And if we don't take a personal care assistant -perhaps the friend we are staying with can assist us -we may be accruing hours of personal care assistant time that will make it appear at our next assessment that we do not need so much cover. Those of us who do need to take a personal care assistant will find ourselves paying for their accommodation and meals -an extra financial burden which is not allowed for.

## *6.2 Solving the problems*

6.2.1 The Personal Profile, held by the individual disabled person, would act as a passport to services and equipment so that no further assessment would be needed.

6.2.2 Include the designation 'registered personal care assistant user' as appropriate in the Personal Profile.

6.2.3 Encourage better training and information for travel and hotel staff, that helps them understand and identify bureaucratic barriers. Involve disabled people in design and delivery.

6.2.4 Review the rules for flying, making sure they are clear, consistent and reasonable.

6.2.5 Establish a method of assessing the extra costs of living as a personal assistance user, adjust benefit payments accordingly.

6.2.6 Review practices, policies and procedures in the travel and tourism industry and ensure that barriers are removed.

## 7 Getting and keeping a job

### 7.1 *Acknowledging the issues*

7.1.1 Most people expect to work at least part of their working lives. Training, career development and job opportunities are reasonably freely available. Once in a job, promotion or relocation can be taken when offered. Businesses are increasingly understanding the need for family friendly policies and flexibility. These do assist disabled people. However, people with NMI tend to need additional support to be able to work, and to have some very particular needs related to their home environment and routine which can impact on their job. Even so, many people with NMI have challenging and responsible jobs.

#### *Access to Work*

7.1.2 Access to Work provides an extremely useful support system for disabled people who are in work or looking for work. Personal assistance is available through the scheme, as is equipment such as voice-activated software. There are still a number of barriers inherent in the rules of the system. Moving jobs, even within the same organisation, can present problems if the disabled person moves from one Disability Service Team area to another. The support package cannot necessarily be transferred from one area to another without reapplication and reassessment.

7.1.3 For those in receipt of Access to Work, the form filling apparently necessitated to satisfy Government audit trails adds significantly to the time and energy required as the contributor of Life Scene 4 highlights. The contributor of Life Scene 12 shows how the frustrations of having to work within bureaucracy can tempt someone to break the law although the outcome is not to the detriment to the Treasury. The rules about who needs to sign claim forms make life overly complicated, particularly where support is provided by a number of individuals or agencies, and it can also be intrusive.

#### *Whose responsibility?*

7.1.4 People with high personal support needs, who have a package of care provided by Social Services, can experience very significant -problems arising from disputes between Social Services and the Employment Service (AtW) as to who picks up the bill. There is no dispute that the individual needs the support but while the agencies fight it out the disabled person is the loser. The contributor of Life Scene 9 highlights the issue.

#### *The bare necessities*

7.1.5 For people who need particular equipment such as orthopaedic supports, appointments with a consultant to get a wholly unnecessary prescription can be very burdensome. Often the places equipment is available from are considerable travelling distance away, necessitating time off. The contributor of Life Scene 4 highlights this. Such equipment is often the equivalent of underwear -and most non-disabled people do not have to take time off work to buy underwear! The rules about equipment such as wheelchairs, and being able to have a 'spare' available in the case of breakdown, can mean that people who rely on such equipment are forced to take off days to facilitate repairs which are often, perforce, unplanned. Even when the equipment is not strictly being used for work, it may be supporting an individual's ability to work, for instance getting down stairs in a lift in order to get out of the house to work. The contributor of Life Scene 4 again highlights these issues.

### *Jumping through hoops*

7.1.6 Some company policies can themselves present bureaucratic barriers when applied inflexibly. One contributor, when applying for a management post in an organisation with a strong safety culture, was required to take a drugs test. The post she was applying for was not safety critical. The company nurse had to oversee the urine test, and the toilet in the medical centre was not accessible. So the nurse, our contributor, and her PA trundled to the nearest public accessible toilet, and locked themselves in for the duration -then had to trundle back again carrying the urine sample in all its glory. On occasions such as these, the desire to get the job may be greater than the desire to protest at such a humiliating experience.

7.1.7 A lack of knowledge, on the part of employers, of the requirements of the Disability Discrimination Act, can create barriers where none should exist. Many employers still look on reasonable adjustments as conferring 'privileges rather than rights' as the contributor of Life Scene 2 highlights. Another contributor saw this, and said it defined her experience precisely. Among other things, the costs of using her electric chair for work -akin to using a private car on company business -was regarded by the company as 'the normal costs of coming to work'. When they grudgingly said she could claim expenses for part of the battery replacement costs -she chose not to do so unless and until it was acknowledged as a true business expense, rather than a 'special' condition for her alone.

7.1.8 Flexible working patterns can be a positive boon to disabled people. However, some companies now have policies requiring flexibility which, for people depending on certain routines to ensure support, or on a significant level of

personal care, or with limited energy, these can be a significant barrier. And some companies have failed to recognise new practices at all. Two contributors reported how they had wanted to become involved in the work of the national charity covering their impairment group, an organisation *for* disabled people. They were conscious that in order to do a good job as a national councillor, and also hold down employment, they would need to split the job between them and applied to do it as 'jobshare'. This would not be entertained.

- 7.1.9 Other company policies can fail to take into account the significant external barriers which disabled people face. An example is relocation packages. Disabled employees who are relocated face a whole range of additional problems which they have to solve such as a lack of accessible accommodation, the need to re- establish support networks, and the time taken to put in place travel and personal support arrangements, on top of all the other stresses acknowledged in moving.

## *7.2 Solving the problems*

- 7.2.1 Identify unchanging equipment needs using the Personal Profile. This would remove the need to attend hospital appointments because the system required it.
- 7.2.2 Use the Access to Work card -currently a wholly redundant piece of plastic -to code the individuals needs for support and equipment at work. In due course this information would be incorporated in the Personal Profile.
- 7.2.3 Enable negotiations for support or funding to take place in advance of taking up a job, so that there is no hiatus between one job and the next, or between unemployment and a job.
- 7.2.4 Work with users of Access to Work and with employers to streamline the system for claiming, and enabling audit of provision.
- 7.2.5 Provide funding for personal assistance from a central and generic 'pot', so that there is no argument between agencies.
- 7.2.6 Recognise that disabled people are 24 hour a day, 7 day a week people. We do not need certain support at work and different support at home -our needs are consistent. Backup systems are crucial if we are to hold down jobs and make a full contribution to society.
- 7.2.7 Establish a system of support for disabled employees who want to object to company policies (like a personal adviser or advocate).

7.2.8 Reduce the speed and number of changes in statutory jargon. Many disabled people still talk of DROs (Disablement Resettlement Officers), for instance, rather than DEAs (Disability Employment Advisors). This can put them at a disadvantage when talking to officials, who treat them as naive or ignorant.

7.2.9 Educate employers about reasonable adjustments and about how policies practices and procedures can disable people with impairments.

8 Having privacy and control over your personal space and body!

### 8.1 *Acknowledging the issues*

8.1.1 Most people expect to be able to close their front door and only invite in those people who they want, or who at least come at their request. People also expect to be able to do things without 'big brother' watching them. Moreover, they expect not to have people 'invading' their body space or doing things with their body which they do not consent to.

#### *Cough it up*

8.1.2 Many disabled people who rely on personal care have no such choice or expectation. It can be as fundamental as breathing. Many people with NMI are prone to chest infections and over many years have learnt how best to manage them, A significant number use a system of assisted coughs to help clear their chests. Recently a number of contributors had come across a new rule introduced by physiotherapists outlawing assisted coughs as 'dangerous'. The alternative offered is to have phlegm sucked from the throat by a tube. This is highly unsatisfactory for many with NMI and begs the question 'for whom is it dangerous -and who assesses the danger?'

#### *Beggars can't be choosers?*

8.1.3 Unless the disabled person has Direct Payments and buys in their own care, they will have to accept whoever the Local Authority sends in. Often, they may not even get on with them. Many local authorities talk of choice and privacy, but the reality is far from the talk. These people may be carrying out very intimate personal care tasks. *It's a case of not even being able to choose who wipes your bottom.* If a male requires a male personal care assistant, this can present significant problems in an inflexible system. The ability for an individual to express a preference is often ruled out by 'the system'.

8.1.4 The choice of timing is also fundamental in controlling personal care as the contributor of Life Scene 5 highlights. But this choice in relation to timing

extends further, when people have a 'right' to -assess you, and collect information from you, before you get fundamental services that you need. Choice of appointment times for assessments is often seen as being the preserve of the agency alone -if a disabled person expresses a preference or indicates they have a prior engagement, or just need to be working that day, they are seen as being awkward, or worse -not really needing the service.

- 8.1.5 Direct Payments -which give disabled people more freedom and control -are only available for those on higher rate Disability Living Allowance. The contributor of Life Scene 5 highlights this bureaucratic barrier. This leads to a lack of control and privacy for a large number of people who need significant support but who do not meet the strict DLA criteria for overnight support.

### *Keeping it to ourselves*

- 8.1.6 Those who provide personal care can have a significant impact in other ways. For someone who relies on others for most physical tasks including getting something out of the drawer, there are no secret places. It is therefore essential that those who go into places which should be 'secret' are bound by confidentiality and have sufficient training to be aware of the need not to comment or make judgement. One contributor in her twenties, for whom bureaucracy was causing significant barriers to her leaving home, highlighted the problem of trying to gain peer support, by e-mail and telephone, for her fledgling sexual activity, when her parents were generally around.
- 8.1.7 Because so much disability provision is means tested, or subject to qualification criteria which differ for every different item, disabled people must give personal information to anyone who asks. For instance, as the contributor of Life Scene 4 highlights, a disabled person has to declare their specific medical condition in order to qualify for VAT exemption. Thus the sales person is privy to information that many disabled people would choose not to divulge. Agencies often do not seem to be able to manage the information that disabled people have to provide, and we must often provide the same information several times. One contributor told of being in hospital, so poorly that, by the time a third person had come up and required her to go through her whole medical history, a friend who was with her called a halt. The contributor of Life Scene 4 also raises this point. Often changed rules can lead to disabled people being unnecessarily put through further information collection processes as the contributor of Life Scene 10 highlights.

### *Abuse in the system*

- 8.1.8 Choice of who provides care to disabled people and the rules under which they work can have a very significant impact on privacy and dignity. Life Scene 13 shows how a 'big brother' approach, which the statutory authorities would say has been developed to protect vulnerable people from abuse, can of itself lead to abuse by the organisation. The situation is significantly more complex when we consider people's freedom to pursue relationships where a third party needs to be involved to provide assistance. It may be that the level of intimate support for sexual activity, or the nature of the relationship, is not 'approved of' by the personal care assistant, and they may then use 'the system' to curtail the individual's choice. Very seldom are disabled people made aware, and certainly not consulted, about issues around harassment and abuse, and the policies in place.
- 8.1.9 Privacy is further compromised in the name of 'quality assurance'. An example of this is provided by the contributor of Life Scene 4 where people monitoring the performance of personal care assistants (Home Care workers) intrude into the disabled person's private life. Even in the name of 'assessment' excessive observation can have this effect as Life Scene 13 shows. And sometimes professionals and care workers can come ostensibly to provide 'support' but have another agenda. The contributors of Life Scenes 10 and 13 demonstrate this.

*Open to scrutiny*

- 8.1.10 Because personal care funding is means tested, if you rely on personal care assistants, you have no financial privacy. Every part of your income, including business income, is open to scrutiny. If you need ILF funding you are required to provide not only personal accounts but also business bank accounts and audited accounts if you run your own business. The issue of paying for personal care is fundamental. To be able to go to the 100, and to get out of bed in the morning we would argue is more vital to life than much of the NHS medical care interventions, which people expect for free as of right.
- 8.1.11 Bad weather prevented one of our members (Life Scene 1) spending her birthday money promptly. So when levels for Income Support were checked she had just over the allowed savings limit in the bank. When she was told her benefit was, as a result, to be reduced by £1 per week she wrote back to say the money had now been spent and she was under the limit. She was then asked to show how she had spent the money to prove she hadn't frittered it away!
- 8.1.12 There are some pieces of equipment of significant importance in a disabled person's ability to carry out normal day to day activities, such as a vehicle, which are not fully funded. People with NMI often require a heavily adapted

vehicle, for which the Motability Scheme provides only a partial grant. Consequently they are often forced to turn to charitable sources for the balance. This can lead to significant local publicity in association with the charity's fundraising which exposes the disabled person in a way which non-disabled people would not expect, just to get out and about.

### *Remote control*

8.1.13 There has recently been a very worrying development for personal care assistance users. This is a decision relating to a situation in South Lanarkshire which concluded that the employer of a personal care assistant paid for through direct payments was the local authority and not the disabled person. This makes a disabled person a 3rd party in the provision of their personal care. The potential impact of this can be seen in life Scene 13 where home carers trying to impose new techniques on the individual made it clear to him that he was not their boss.

8.1.14 In the South Lanarkshire case, the disabled person was guilty of sexual harassment, but the Council was held responsible as the employer. It seems that when disabled people control their own lives they are just not allowed to do it badly. Many employers are bad employers, and disabled people will number amongst them. Generally, control is not taken away from an employer as a result of bad management, though there may be some penalty, such as a fine. If it was a concern in this case, the response should have been to hold the disabled person responsible for his actions as an employer, and to disallow him direct payments in the future (perhaps for a set period).

### *Whose Health and Safety?*

8.1.15 Decisions on supply streams seem to be based on assessing the needs of the sick non-disabled person. Our needs as disabled people, with specific individual requirements arising from the way we manage our own impairment, are ignored. These bureaucratic decisions do not look after the public pound effectively, because of the knock on effect it can have on our independence or resultant health care needs.

8.1.16 Health & Safety and similar directives often prevent us using equipment and the handling methods which is best suited to our particular needs. Two members have used band slings for a hoist safely for over 40 years. They are now being told that the Medical Devices Agency say band slings are unsafe. This makes them very difficult to obtain and an indemnity must be signed before they can

be purchased, and yet no other design of sling meets these members particular needs.

8.1.17 The contributor of Life Scene 13 had particular manoeuvres "outlawed" by social services care staff as being not compatible with their lifting and handling training, despite the fact his particular situation had not been risk assessed. They wanted to use new lifting and handling equipment on him without any prior consultation or assessment.

8.1.18 Sometimes equipment is no longer supplied, but the alternatives provided do not suit our particular needs. For one member it was a ripple bed which was no longer authorised for purchase by the Health Authority. The suggested substitute simply did not meet their particular needs and their health was threatened. Another member could use a particular type of bedpan. The supply of this was discontinued as it was said to be "illegal". She was eventually forced to get a craftsman to make her one. Another member found that a hospital had decided only to purchase and allow the use of disposable bedpans. She could manage a conventional bedpan, but not a disposable one.

## 8.2 *Solving the problems*

8.2.1 Allow the disabled person to define the nature of the care they want provided. As long as this does not involve criminal activity, it is clearly outlined to a prospective personal care assistant, and they agree to provide it, this agreement should remain between the disabled person and their personal care assistant. Other agencies' 'rules' should not be applied.

8.2.2 The adoption of the Personal Profile would remove the need for excessive assessment. It would prevent people with a clearly progressive condition being re-assessed unless they requested it

8.2.3 Use the Personal Profile to specify a disabled person's VAT exemption status, removing the need for intrusive declarations.

8.2.4 Use the Personal Profile to specify the disabled person's needs in relation to transport. Where local provision varies in the availability of accessible transport, funding for private vehicles could also vary accordingly. Funding for private vehicles should be available on a top-up basis, according to the nature of vehicle and adaptations identified in the Personal Profile.

8.2.5 Change the focus of applications away from requiring disabled people to "prove worthlessness" in order to get services. Disabled people must be encouraged to take a more positive view of themselves.

- 8.2.6 Make direct payments available to anyone requiring personal care, regardless of the level of care required.
- 8.2.7 Establish beyond question that basic personal care is a right and should not have to be funded from an individual's own purse.
- 8.2.8 Ensure greater openness and consistency in the system of care and support provision, through better management and the involvement of disabled people.
- 8.2.9 Allow disabled people to understand the nature of risks they are taking and choose whether to take those risks for themselves. Where the risks relate to the health and safety of personal care assistants, the risk assessment should be relevant in all the circumstances of the individual, and not a blanket stipulation.
- 8.2.10 Provide appropriate information, and if necessary training, to disabled people receiving direct payments so they can understand the nature of the responsibilities they are taking on. Then allow them to fail in those responsibilities and take the consequences. Rights without the accompanying responsibilities are not rights at all.
- 8.2.11 Involve disabled people in the development of assessment and quality procedures for home care.
- 8.2.12 Use qualified disabled trainers to train staff in the provision of home care, and in the application of assessment and quality procedures. Staff should not provide care, or implement the procedures, without appropriate training.
- 8.2.13 Enable disabled people -in particular equipment users -to be involved in Medical Devices Agency decisions.

## 9 Paying for it all

### 9.1 *Acknowledging the issues*

- 9.1.1 Although many people have additional costs to meet over and above those purely to maintain life -eating and keeping a roof over your head -most are taken on with an element of choice. Even additional child care costs are in most cases a result of choice.

### *Balancing the budget*

- 9.1.2 For most people with NMI there are fundamental needs which can only be met by bringing in additional resources. In order to live, many of us have money or

resources from at least three sources - local authority, DSS, and Independent Living Fund (ILF). Each one of these has their own requirements and checks, which the individual must find the time and energy to co-operate or comply with. For instance one contributor's local authority, which we know is not unique, requires details of every cheque number and payment made with direct payment monies as well as a summary sheet at the end of each month. The contributor of Life Scene 5 also highlights barriers in this area. Very many of the rules governing the benefits and other resources on which disabled people rely are complex and unpublished. Even those administering the systems are often unaware of the 'small print'. Also policies vary from area to area between Local Authorities, so there is no guarantee that a care package arranged in one locality will be able to be replicated in another.

- 9.1.3 When, in order to just live you need to rely on so many external sources of support and, in order to qualify for this support, jump through so many bureaucratic hoops, it is extremely stressful. It is an inescapable fact that for many people who rely on others for personal care needs, at times of life where stress levels are acknowledged to be at their highest -divorce, moving, bereavement -support arrangements have to be varied and the additional bureaucratic barriers negotiated. The contributor to Life Scene 5 commented that what should have been the most exciting time of her life was turned into a nightmare.

#### *Added Tax*

- 9.1.4 Many responding highlighted the cost of ensuring even basic personal care. When people are required to pay themselves or pay through direct payments, and use agency care, they have an additional barrier. If the level of care required is not nursing care, which few people with NMI need to any extent, VAT is payable at 17.5% on top of the agency fees. It can hardly be considered a luxury or a supply of choice, to get someone in to take you to the 100 and wipe your bottom. People found it very hard to understand how the Treasury could justify this taxation.

#### *Whose money is it anyway?*

- 9.1.5 One issue highlighted by one contributor is the contribution of benefits to family finances. Even when he and his brother were in their 30s, they were still living at home and only receiving pocket money from their parents. This is a significant barrier to independent living, but it is very hard to break through when there is little understanding of the power balance issues within family relationships.

### *Paying twice*

9.1.6 A disabled person is not an island, and often their personal relationships are subjected to significant additional stress which can lead to a break up. The contributor of Life Scene 7 shows how financial intrusion can be caused. A partner is expected to contribute towards personal care from *their income* even though they will almost certainly, by their very existence, be reducing the individual's need for personal care. It is a double jeopardy. It seems to be treated in the same way as a partner's responsibility to contribute in the case of Income Support, but it is *totally* different. Income Support relates to household costs, which will be shared where there is a partner present. Personal care, however, is about individual need that is not shared. The contributor of Life Scene 8 shows how bureaucratic barriers which their partner was encountering impacted significantly on their own working life.

### *Who can we pay?*

9.1.7 Some disabled people experience significant barriers from rules about who can be paid for what. The contributor of Life Scene 11 highlights problems in relation to housing benefit, and the contributor of Life Scene 3 highlights issues about Invalid Care Allowance being paid to pensioners. There are also issues around who can be paid from Direct Payments. These were introduced as a protection measure but which can cause individuals significant problems, particularly in achieving flexibility in emergency cover.

### *Saving for a rainy day*

9.1.8 Rules around the accumulation of capital cause people significant problems if they have a need for equipment, which is not fully funded, and which is costly. People with NMI very often require heavily adapted motor vehicles, significantly complex electric wheelchairs, environmental controls, computer equipment to enable them to access leisure activities, lifts and so forth. If you require a combination of these, which also need repair along the way, to be able to accumulate only limited capital makes life an unnecessary nightmare -that is if you have the ability to accumulate capital. Even seasonal variations in care requirements can cause problems. For instance, if you have been assessed to receive money to enable you to have gardening done it is likely to accumulate over the winter months for use in the growing season. Similarly funding for personal care for going away, which may mean paying as many as three people full time for the period as well as funding their accommodation, has to be built up.

9.1.9 Most people would expect to be able, and indeed the Government expects individuals, to save and provide for a time when they cannot work. For most non disabled people this will be the 'normal' retirement age. However, many people with NMI cannot expect to continue working to that age. The impact of ageing on their impairment will mean that they will need to look to early retirement. Standard pensions, which benefits regulations allow us to invest in, will not meet our needs for an earlier retirement date, and yet accumulating our own 'pension fund' is outside the rules.

### *Do-if-yourself*

9.1.10 If you require an alteration to a building, Disabled Facilities Grants tend to be out of the reach of anyone who is not on benefits income alone, and yet there is often little choice about needing work done, and the health impact of not having it done is significant. In addition it is not permitted to apply for a grant until you have the property, which for most people means you have moved into it as we do not have resources to own two properties at once. This can significantly inhibit people's ability to move.

### *Be my guest?*

9.1.11 If you require to take personal assistance with you, if you go, for -example, to a theatre you end up having to pay for their seat and any refreshments needed. The funding available does not in general meet these needs, and many disabled people have gratefully accepted concessions from leisure venues, travel operators, and so on for having the additional person with them. This charitable approach is not one that we believe is appropriate.

## *9.2 Solving the problems*

9.2.1 Reassess the extra costs of disability -as these are not fully covered by the Disability Living Allowance. Use the Personal Profile to identify the level of extra costs for the individual disabled person, which would be used in funding the personal care package.

9.2.2 Use the Personal Profile to identify a disabled person's needs in isolation from any available assistance they might have from, for example, a partner. When circumstances change -such as the partner moving out -the Personal Profile would enable instant assessment of the additional support required, and remove the additional distress of dealing with agencies at this time.

9.2.3 Grant VAT exemption immediately for personal care and independent living services.

- 9.2.4 Establish beyond question that basic personal care is a right and should not have to be funded from an individual's own purse. Receiving personal care is not a choice for the disabled person, but a necessity for living. No contribution should be required from partners or other family members who will probably already be contributing in kind. It must be recognised that personal care does not form part of the marriage contract, and expecting it to do so will put additional and unnecessary strains on a marriage.
- 9.2.5 Allow disabled people to pay those who provide them with personal care - regardless of relationship. Any payment would constitute the personal care assistant's income and affect benefits and/or be taxed as appropriate.
- 9.2.6 Replace Invalid Care Allowance with appropriate funding for personal care over which the disabled person has control.
- 9.2.7 Recognise that advocacy and peer support are fundamental for a disabled person in any negotiations with agencies.
- 9.2.8 Train "professionals" to recognise and understand family dynamics as they affect independent living.
- 9.2.9 Ensure openness and consistency in the rules for funding care across geographical areas.
- 9.2.10 Use the Personal Profile to identify the disabled person's need to accumulate capital to pay towards new equipment, for example wheelchairs. Although this Report recommends that personal care provision should be free, accumulating capital is still an issue for those, for example, on Income Support, where levels of savings affect benefit received.
- 9.2.11 Increase the flexibility of Disabled Facilities Grants (DFG). Legislation has only just been brought in to require housing to be built to access standards, and this will take a long time to work through the housing stock to any useful extent. Until that time, it should be recognised that disabled people will need adaptations to housing, and this should be funded. The Personal Profile could identify the nature of housing required, and funding from the DFG provided in accordance. Local authorities could take account of the general availability of accessible housing on the market in their area when setting the level of grant, and this would help to prevent 'scrounging'.

9.2.12 Use the Personal Profile to identify a disabled person as a personal care assistance user. Some allowance could then be made for social excursions, to pay for personal care assistants.

9.2.13 Involve disabled people in the further development of the direct payments system, so that they can bring reality to the discussions in relation to seasonal variations, saving to go away, and so on.

*D. Untangling the agencies involved*

1. None Escapes

1.1 In this Report we have not identified those agencies responsible for implementing the suggested solutions. This is because the removal of the barriers identified can, and should, be tackled at a number of levels and by a number of agencies. An example of this is in C1.2.1 highlighting the need to achieve an increase in choice and control for disabled people.

1.2 However, to assist those reading this Report, we review here the agencies that could dismantle the barriers, many of which are complex and extend into several areas of responsibility.

1.3 We would encourage agencies to be bold and creative in working together to break down these bureaucratic barriers. It is sometimes easy to shift the blame where more than one agency is involved, or to feel powerless to effect change. But if the agencies are powerless, how much more so are the disabled people whose lives are profoundly affected by this inertia? And meanwhile, the number of barriers grows, and they extend further and further into the fabric of our social institutions.

2. National Government

2.1 Virtually all Government departments are affected by this Report.

2.2 As we would expect, there are a significant number of barriers identified which are within the province of the Departments of Health and of Social Security. Instances of these are found extensively in C1 and C8.

2.3 Also the Departments of Trade and Industry and of the Environment, Transport and the Regions are also involved on a number of solutions identified. Many instances of these are found in C3 and C4.

2.4 The Department for Education and Employment has a range of responsibilities which touch on the people with NMI. Examples include C7.

2.5 The Cabinet Office has a role in recruitment to Government advisory bodies and non-departmental public bodies. There is a significant need to consider the opening up of these bodies to people with firsthand experience of the barriers. An example of this is C8.2.13.

### 3. Local Government

3.1 With its responsibility for social care and housing in particular, local government has the key to a number of solutions. Some of the issues relate to commissioning roles within local government, and others to service delivery. We have not attempted to split them up as many have implications for both.

3.2 Examples of local government issues are included throughout the Normal Day-to-Day Activities. Section C1, C2, C4 and C8 each have a very significant number but they appear in other sections too.

3.3 There are also a number of solutions which affect formal Joint Planning processes with the NHS. These include C1.2.14.

### 4 NHS

4.1 The NHS is responsible for a significant number of services essential in enabling people with NMI to achieve independent living.

4.2 We recognise that the responsibilities sometimes lie with Health Authorities and Primary Care Groups in their commissioning roles, and some with NHS Trusts and Primary Care providers responsible for service delivery.

4.3 Some examples of NHS solutions are C3.2.1 and C3.2.2

### 5. Employment and Training Service Providers

5.1 The Employment Service is the key provider of employment and training opportunities.

5.2 Many people with NMI have to spend so much time and energy negotiating bureaucratic barriers relating to just living. Perhaps this is why a high number of barriers were not identified in the employment and training area.

5.3 However, there are lessons which can be learnt, for instance, C5.2.6.

5.4 There are also a few specific barriers highlighted, primarily found

in C7.

## 6. Private Sector

- 6.1 Despite the fact that by far the majority of barriers identified are within the jurisdiction of the statutory sector a significant number were identified in this sector.
- 6.2 Once again, lessons can also be drawn by this sector from the experiences highlighted in other sectors, particularly those private sector organisations providing health and social care.
- 6.3 Some instances of barriers and their solutions within the private sector were highlighted in relation to travel and transport (C3 and C6) as well as banking and the retail sector (C5).

## 7. Third Sector (Voluntary and Not-for-Profit)

- 7.1 This sector, where it provides services, can again learn from other sectors.
- 7.2 Disabled people and *their* organisations -those controlled and run by disabled people -could play a vitally important role in assisting with the dismantling of barriers. Disabled people's groups are a significant and vital resource but in order to play an effective role they must be properly resourced. It is vital that those who wish to act upon the recommendations about building up peer support, involving disabled people in reviewing processes, and so on, take this on board.
- 7.3 This Report started off as a small project for which Muscle Power! had funding to cover printing and distribution. It has grown but the resources available have not. It has been a significant drain on the personal resources of all those involved, who have been doing it on a voluntary basis in addition to living and working. Nonetheless, the Report shows what could be done if sufficient resources were provided to disabled people and their organisations.

## 8. Disability Rights Commission (DRC)

- 8.1 The publication of this Report is planned for the month in which the Disability Rights Commission starts work. We believe that a significant number of issues raised should be taken forward by the DRC, as well as by the agencies and sectors involved.

## E. *Life Scenes*

*Some of those who provided their stories were happy not to be anonymous. However, we have taken the decision to anonymise all the contributions. This is because they could be anyone in any place in the UK. Identifying the place leads to the danger the example will be dismissed as a "one off 'there that couldn't happen here, and our contention is -it could.*

## Life Scene 1

When I received my Income Support Review I was required to send in Bank statements as proof of savings. Unfortunately, I had a little over the three thousand pound limit, as I hadn't spent a rather large Birthday cheque I received from my family.

I then heard, that because I had 'disposable income' my weekly benefits were being cut by one pound, and I was to return my order book for this to be done. When I rang to tell them my savings were now below the limit I was told I would have to prove what I had spent the money on -in case I "frittered it away"!

I felt this was an infringement on my privacy, but complied as I felt it was worth it to get my full entitlement back. I was, also, told not to return my order book.

I didn't hear any more from them, after I had sent in new bank statements, receipts and covering letter, until 3 months later when my order book ran out and I didn't receive a new one. When I rang I was told I hadn't been issued with a new book as I hadn't returned the old one as requested! I am afraid I almost lost my temper as I was being spoken to as if I was a scrounger. I did, eventually, get an agreement that I had been re-assessed (!) and they could see no reason for them not to give me a new book.

This was not the end of the saga as, to date, it's like this -yes, they issue a new order book, but my transitional protection payment of over a hundred pounds a week have been left off! More phone calls, more letter writing and more hassle for me. Especially as the payment is part of my weekly care package!

Two points come out of this-

1. Isn't it time the savings limit for people on Income Support was raised? People like me have to keep 'extra' money to cover repair costs on our powerchairs, electric beds and converted vehicles, to name a few, and that's expensive.
2. When are the DSS computers going to be up-dated to include the transitional protection payments? Nearly every year, since the change from Supplementary Benefits, I have had to remind my local office to include mine.

## Life Scene 2

### *Bureaucratic Barriers in Higher Education*

#### *Preamble*

I work in Higher Education as a lecturer in Cultural Studies. Universities and colleges in Britain generally like to think of themselves as liberal places, largely free from discriminatory practices. The rhetoric of mission statements reinforces this view. The reality is somewhat different. What emerges from my first-hand experience and in-depth discussion with disabled academics is how unequal British higher education is.

Dispelling the myth of universities' and colleges as liberal institutions is a prerequisite to addressing the multi-faceted problem of disabilism in higher education. The stakes are high. We know that higher education is a powerful determinant of life chances. We know, too, that disabled people are chronically underrepresented within the sector.

So what can be done to dispel the myth? Well, one way is for disabled academics to speak out about their experience in higher education: to give an account of the barriers and the blows. And, in the absence of systematic monitoring to ensure that higher education institutions are not disabilist, that they are meeting their legal responsibilities under the DDA 1995, and that their mission statements or disability equality policies mesh with the reality, relating actual experience is one of the few ways to draw attention to the barriers disabled people face.

A code of practice recently drawn up by the Quality Assurance Agency for Higher Education, *Students with Disabilities* states that higher education institutions will be able to use the experience they have gained in exercising their responsibilities towards employees under the DDA to improve participation by disabled students. If some universities and colleges are failing to respond adequately to the needs of disabled employees, then what hope is there that they will consistently meet the needs of disabled students?

Even in a Church foundation college like my own, policies and practices are often dictated more by profits than principles. Clearly some institutions will be spurred on to improve the lot of disabled students by thoughts of future financial premiums attached to them. As there is no talk of pots of gold attaching to recruiting and retaining disabled academic staff, disabled academics frequently find themselves exposed to all sorts of shenanigans, all the more so when budgets are tight, as I discovered to my cost. Will a similar fate await some disabled students if the much talked of financial premiums fail to materialise?

In describing some of the barriers I have come up against in the fight to keep my job as a lecturer I shall adopt the "life episodes/events" model.<sup>1</sup> The advantage of this model is that it enables us to narrate life situations rather than isolated events. Bureaucratic barriers are more like the Berlin Wall than Becher's Brook: they are a symptom of a complex situation, not isolated obstacles to be overcome. The "life episodes/events" model offers a more rounded approach to identifying some of the many barriers disabled people confront in universities and colleges.

The two "life episodes/events" I have decided to focus on here are: returning to work under the provisions of the DDA 1995 and the transition from one academic year to another. The reason for this particular choice of transitional events is that I know from discussions I have had with disabled academics in other institutions that the barriers I have encountered are ones others have met with, too.

### *Life Episode 1: Returning to work*

Without the good offices of Natfhe's regional universities official, I may well have ended up swelling the ranks of benefit claimants that Social Security Secretary Alistair Darling is so anxious to curb. I had been off work for nine months or so when I first approached my employer, aided by Natfhe, with a view to returning under the provisions of the DDA 1995. I didn't have a definite diagnosis for my condition. I had profound muscle weakness and signs of muscle wasting. Fortunately, diagnosis 1S not the lynchpin of the Act, so that was one barrier I didn't have to overcome. This is just as well because some neuromuscular disorders, such as MS or ALS, may take years to diagnose. The BMA puts the mean time between onset and diagnosis of ALS or motor neurone disease as it's more commonly called in Britain as four years.

The negotiations with my employer took all of four months. There were the obvious barriers that disabled people who can and want to work confront with depressing regularity: the assumption that disability equals inability or that "reasonable adjustment" confers privileges rather than rights. However the biggest barrier during the negotiation phase was that college managers had little or no knowledge of the Act let alone how to implement its provisions. This made the negotiation process doubly distressing for me. I often felt like a patient being operated on by wannabe surgeons with no prior medical training. It also made the negotiation process much more protracted and peppery than it might otherwise have been. In fact my occupational sick pay ran out a month before the negotiations were concluded.

The danger in seeing this lack of training of managers in disability issues as a barrier more akin to Becher's Brook than the Berlin Wall is that it obscures the complex causes of social exclusion in higher education. One of these causes is the nature of

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<sup>1</sup> Marilyn Howard, 1999, *Enabling Government. Joined Up Policies for a National Disability Strategy*, The Fabian Society

bureaucratic corporatism itself. One of its effects is that it has encouraged a culture to take root where rhetoric is often alarmingly out of sync with reality. Universities and colleges are experts in devising policy statements but many are amateurs when it comes to implementing them. Indeed some institutions seem to think that good practice flows naturally once policies are put down on paper. Certainly my own experience bears this out.

Following the lengthy negotiations with my employer an agreement on 'reasonable adjustment' was eventually drawn up. However none of the reasonable adjustments were in place on my first day back at work. As one of the agreed adjustments was to relocate my office situated in an attic six flights up to the ground floor the failure to implement the agreement made it impossible for me to work. On the face of it the barrier that prevented me from working was a physical one. But physical barriers are bureaucratic ones as well. And bureaucratic barriers are barriers that bureaucracies throw up.

Since then, training for managers on disability issues has been introduced (i.e. the College has put on one or two staff development sessions for senior managers) but unless disabled people are invited to participate in these programmes they are in danger of becoming little more than exercises in bureaucratic corporatism. Increasing awareness and knowledge of disability is of course vitally important, but it should not be seen in itself as the solution to transforming the situation of disabled people in higher education.

Bureaucracies by their very nature tend to be rigid structures. Meeting the needs of disabled people demands flexibility. The word 'bureaucracy' means quite literally power to the desk. Disability on the other hand all too often means disempowerment. As bureaucracies, universities and colleges are both part of the problem as well as potential providers of solutions. The myth of their being liberal institutions at heart in effect obscures the gaps between policy formulation and implementation and masks the very real suffering that can flow from the failure to institute good practice.

### *Life Episode 2: The transition from one academic year to another*

After many battles I succeeded in returning to work. Although the College was slow to make some of the agreed adjustments, my office was eventually relocated to the ground floor and I had a computer up and running at home. The euphoria that accompanied my return was however short lived. I soon realised that the problems that I had encountered in moving off sick leave back into work were in fact only the first wave of bureaucratic barriers. There were more to come.

The transition from one academic year to another, which back in my non-disabled days generally went without a hitch, proved even more fraught than the movement

between being on benefits and being back at work. The transition does not coincide with the chronological movement between one academic year and the next. Normally it is effected some time before the end of the summer term. Basically it involves working out timetables for the coming academic year. Cedric Pugh, Professor of Urban and Regional Studies at Sheffield Hallam University, highlights the problems surrounding this common life episode for disabled academics in his submission to the House of Commons' Education and Employment Committee, *Opportunities for Disabled People*. "Bureaucratic rigidity", writes Professor Pugh, "sets up barriers against 'reasonable adjustment' and requires unnecessary reconsideration of .teaching year-on-year. This places stress upon disabled people, and contrasts with the treatment of disabled students who are frequently studying within adjusted conditions." <sup>2</sup>

In my instance, the rigidity of College structures was compounded by the sudden emergence this year of a budget deficit. Senior managers began to plead impecunity or point to the impracticality of arrangements already agreed; reasonable adjustments were reinterpreted as restrictions on my ability to fulfil my contractual obligations: with the result that I was asked to make a formal declaration to the effect that I was under-performing. Such a declaration, so I was told, would enable the College to tap into financial premiums from the DfEE that attach to disabled employees who under-perform.

What they had in mind was the Supported Employment Scheme. Apart from the fact that declarations of under-performance form no part of this scheme, the scheme itself is designed to assist disabled people otherwise unable to work in open employment: a category which I clearly do not fall into.

What began as a series of bureaucratic barriers thrown up by College during the first transition became a veritable barrage during the second. As I write this, a little over four weeks before the beginning of a new academic year, the transition between one academic session and another has still not been satisfactorily effected.

### *Conclusion*

Universities and colleges are keen to trumpet mission statements but all too often tardy in their implementation of them, leaving already hard-pressed individuals to battle time and again against bureaucratic barriers or to wage their own rearguard campaigns to ensure that the DDA is accepted and its provisions instituted.

A Disability Rights Commission with muscle power to set targets, monitor provision and penalise higher education institutions that fall short of best practice would be a more effective way of breaking down bureaucratic barriers. (It would also enable

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<sup>2</sup> Cedric Pugh, 1999, *Opportunities for Disabled Academics: The Morphology of Cases*, Submission to the House of Commons' Education and Employment Committee

people like myself to use what muscle power they have to do their job rather than expending it on battles to keep hold of it.) In the absence of such a Commission, higher education will continue to clothe itself in the myths of liberalism; to hide behind its mission statements, which serve as alibis to the sector.

### Life Scene 3

I was so pleased to hear that you are compiling a report on the disabling nature of bureaucratic structures set up without reference to our needs. The following are some areas of difficulty I have come across:-

#### *Income Support*

The savings limits of £3,000, at which benefit is reduced, and £8,000, at which it is stopped altogether, have not risen with inflation thus reducing the real value of people's maximum savings.

These limits are the same for disabled and non-disabled people taking no account of the fact that disabled people may have bank/building society accounts in which they save for adapted vehicles (costing up to £30,000) or powered wheelchairs (up to £20,000) or in which they hold the direct payments made to them to employ their personal-assistants.

#### *Mobility Allowance (MA)*

MA is paid at the same rate for semi-ambulant people and wheelchair- users. This takes no account of the fact that the most severely disabled people need very expensively adapted vehicles and powered wheelchairs rather than, for example, an ordinary, automatic car. It also doesn't allow for wheelchair-users having greater expenses when they have arrived at their destinations, e.g. if my husband and I visit my mother-in-law in London we cannot stay at her inaccessible flat but have to pay for very expensive hotel accommodation.

MA goes up annually with October's inflation figure (October being a month of traditionally low inflation, anyway) but each budget petrol goes up by much more than inflation. As petrol is one of the major expenses for many MA recipients (especially as large, heavily adapted vehicles have a low MPG) this means it's real value is reduced annually.

#### *The Mobility Scheme*

This scheme, supposed to ensure disabled people can buy suitable vehicles, can lend a maximum of around £7,600. Anyone needing a heavily adapted vehicle, costing £15,000 to £30,000 has to find a huge deposit.

The Motability Scheme does not allow for someone needing to purchase a powered wheelchair and an adapted car at the same time as needing to hold money back to cover running costs.

The hire purchase APR on the scheme is only about %% below ordinary building society rates which seems rather expensive.

Drivers using the scheme cannot get a no-claims bonus on their car Insurance.

### *Local Transport*

#### *Ring & Ride*

These profoundly inadequate schemes are supposed to make up for the lack of accessible public transport. They fail because:-

They have to be booked up to a fortnight in advance of the date on which you wish to travel.

The vehicles are not allowed out of their own borough so, if like me, you live in one area, have a GP and family members in another and an art-class and a dentist in a third local authority's you are practically housebound.

#### *Buses*

Most buses are still inaccessible. Many areas never see an accessible bus.

So called wheelchair-accessible buses usually have no method for securing wheelchairs to stop them rolling about. This is very uncomfortable and potentially dangerous.

Orange-badge holders (in my town at least!) are only entitled to a concessionary bus-pass if they give up their orange-badges in exchange. These are hardly interchangeable as a bus-pass would cover travel in the local area whereas the orange-badge is recognised across the whole UK (except parts of London which hardly seems fair) and much of Europe. No concessions are available on the buses for personal-assistants.

#### *Travel further afield.*

## *Trains*

The access to trains and railway stations and the concessions available are so poor that I have travelled on a train once in my 33 years -in the Guards' Van with a racing bike falling on me.

## *Air travel*

I have never found any free parking (even for picking-up and dropping- off) at an airport.

Toilets on aeroplanes are not accessible. This is a particular problem for female wheelchair-users during long flights as men at least have the undignified option of using a bottle to urinate in their cabin.

Airlines refuse to carry certain types of wheelchair batteries

Wheelchair-users are not able to travel in their own chairs which may be adapted for postural or balance problems.

Wheelchair-users are lifted by staff who do not understand that people with different impairments may need different lifting techniques to prevent injury. Personally I won't allow anyone who doesn't know me to lift me and don't enjoy being lifted in public.

Some airlines charge wheelchair-users for the use of airport wheelchairs in which to be taken to the aeroplane. This is completely unfair when they are not given the option of using their own chair.

Travel agents often find it difficult to provide clear information on access to hotels etc. abroad.

It is very difficult to arrange health insurance for holidays abroad if you are disabled (or, indeed, for a mortgage or anything else). Most companies won't even consider you and others charge whatever they fancy. This is equally true of car insurance for an adapted vehicle.

## *Access*

### *Building generally*

Many shops, schools, theatres etc. are still profoundly inaccessible. Even where grants to improve access are available there is often a low take up.

### *Toilets specifically*

Toilets designed for use by disabled people are often inaccessible to severely impaired people. Many disabled people need room for an assistant and/or equipment (such as a folding bench to lie on in order to undress) but cubicles for wheelchair-users are all designed with only the space required for one independent wheelchair-user in mind.

### *The Radar Key Scheme*

Toilets for disabled people are usually locked to everyone else and keys are available for disabled people to use. If you don't have your own key (£3 from Radar) it is probable that you will have to queue in a shop or go out of your way to some information desk (which may be busy) to borrow a key. This is far from ideal if you are desperate for a pee! It is also embarrassing to have to ask to be given access to the toilet in front of a bunch of onlookers. I'd rather that the odd able-bodied person sneaked a pee in 'our' toilets than have this inconvenience.

### *Education*

Why are so few schools wheelchair accessible? It is not good enough that some 'designated' schools have access. This is still divisive and, anyway, children are not the only people who need access. What about disabled teachers? And disabled parents with able-bodied children, who cannot attend school functions or become school governors? What about all the people who, having been deprived of a decent education in the first place by being sent to 'special' schools, cannot attend night-school classes held at inaccessible schools? Why are children still being sent to 'special' schools? And why, when someone has managed to get an education and find a University with half decent access, are there so few support services available to enable severely disabled people to go into Higher Education? If one relies on one's family for personal assistance one is unlikely to be able to go to college. Disabled people need direct payments for personal assistance at all stages of their lives Which brings me to:-

### *Independence*

#### *ILF*

The ILF allows a top-up grant (to £500 per week) to be added to 'care' services provided by local authorities in order to enable disabled people to live in the community. This doesn't allow for a very small number of disabled people needing more the £500 worth of services a week. Nor are the services provided by the local authorities written in stone. For example some councils will provide personal

assistants within the disabled person's own home while others are less obliging. Even the authorities providing assistance at home often don't allow the disabled person to choose their own staff and staff are usually changed every three months or so. This is intensely inappropriate for people needing highly personal and intimate help. The ILF also works as a great disincentive to work as qualification is based partly on income. If it was not means tested many users would be able to take jobs but, as things stand, the very assistance which may make work possible is withdrawn the moment paid employment commences. Married disabled people with working partners are put in an equally strange position -for my husband to work I need full-time help at home, but, if he's working we don't qualify for ILF because of our income and if he's not working we don't need ILF because he can assist me on a full-time basis. My husband having been offered a job after a period of being on Invalid Care Allowance (ICA), I applied to our local social services department to see what help was available to enable my husband to accept the post. I was offered a day centre place (!) or 'pop-ins' (not Mary Poppins, I hoped!) 'Pop-ins' involved a mobile assistant calling for ten minutes at a time 'every two hours or so' which is so staggeringly inadequate (for someone for whom a trip to the 100 takes half an hour minimum with assistance from somebody who is used to me) that I turned it down flat. We manage by my mother (aged 65) and her sisters (aged 67 & 70) coming in on different days of the week. Because they are all OAPs none of them can claim ICA as they are already getting state pensions. This is ridiculously unfair as they would still get their pensions whether or not they came to help me. Why can't people be paid ICA as well as another benefit?

### *Benefit Changes*

#### *How they will affect me*

I get Severe Disablement Allowance (SDA). If I find a job and try to work but it doesn't work out and I need to go back on benefit within two years I will be disqualified from getting SDA and will not receive Incapacity Benefit (IB) as I will not have paid enough National Insurance contributions. This is hardly likely to motivate me to work.

#### *How they will affect people like my sister-in-law.*

My sister-in-law is terminally ill. She gets a reduced occupational pension because she has had to finish work before retirement age and she gets Incapacity Benefit. She has a £60,000 mortgage which she could not afford without both her incomes. Although she will not be affected by the new rules, people in her position in the future will not qualify for IB thus they could be made homeless due to falling ill. This is outrageous and must not be allowed to happen.

It is hard to know where to begin because life is such a logistic nightmare for all of us. I will try to do it in some sort of logical sequence - in the home and outside the home.

In the home -aids and appliances. The problems are: the number of different agencies that you have to go to in order to get appliances, even if you are paying for the appliance. A small example is a soft collar which I have to wear every night. If I want a new one I can either get it from a physiotherapy department i.e. I have to go to the doctor to get a letter then go to the hospital, another appointment, another wait, another phone call. And of course they won't give you two so that you can wear one and have the other in the wash. It was OK when I was regularly going to the hospital but I don't bother anymore -waste of time. So I buy these collars. But can I get them in the high street -no. I have to go to central London. The same goes for fake sheepskin that I have to have on my chair.

We all know the problems of wheelchairs and the length of time for repair. Despite the fact that the electric variety can cost the same as a small new car, the service available is quite different. Only a few weeks ago, within the first year since purchase (and therefore under warranty) the front wheel of my chair broke off. Luckily there were five burly workmen nearby who lifted me home. Also, thank goodness I have a second electric wheelchair, otherwise I would have had to stay in bed.

The break happened on a Friday. The chair was not collected until Monday. I then heard from the repair people that the spares would not be ready for several weeks. I phoned the manufacturers and got the same answer. I insisted on speaking to the manager. It was a week and several phone calls later -expensive, long distance -that the new wheel was eventually delivered to the repair people, who returned my chair that day. This is not an isolated incident, nor is it the first time that wheels have come off new chairs. In fact I have had a terrible time with wheelchair manufacturers. The suppliers/repairers that I use now are fine and work as quickly as they can but there are others who are ghastly. A well-known London based outfit I have experience of are incredibly incompetent. This is not just my experience but that of a work colleague. He needed a new seat to his manual chair. Thirteen weeks and two wrong-sized ones later he has got a new one.

The emergency service on my lift is supposed to respond instantly but now the calls are routed to the Local Authority who have to authorise the repair. So if the lift breaks down out of office hours I am in a mess - confined upstairs or downstairs. (You can manually get the lift down). Obviously for all these emergencies it is essential to either have a mobile phone or someone with you. Costs of a mobile phone are quite high.

I have never used local authority' personal assistant services or any others. I just could not cope with the bureaucratic nightmare that would follow, nor could I tolerate

having to be in when the home help came or put up with the fact that she could not clean my children's rooms because they were over 9 years old, or take down the curtains to wash because she would contravene health and safety regulations. Recently, in my borough, the PA scheme run by the local authority was subject to an external evaluation. The evaluators insisted that they had to watch the PAs in the process of intimate interventions. It was not until our CIL intervened that this was stopped.

I have a Ford Transit van which is converted to allow me to sit in the front and has a hydraulic lift. But Ford dealers will not service the lift so I have to have someone different to do that -another callout charge!

I often travel by train. On suburban lines I just turn up at the station and expect to be put on the next available train. On long-distance I sometimes phone but that is very difficult because the opening hours of the customer service desk are extremely limited. When they are open the lines are busy or they don't answer. They ask you how you are arriving and how you are leaving the various stations, instead of leaving it to you to ask for any extra help that you may require. If you do not phone they can be extremely rude or treat you like a naughty child. And if there is no trolley service on the train, nobody comes to ask you if you would like something to eat or drink.

I am fed up with seeing adverts etc. about holidays, entertainment, eating places, etc. etc. which never say whether they are accessible or not. And I get even crosser when the tour operator or whatever then ask you to send in for a special brochure.

A year or so ago I wanted to move house. Extensive searches for accessible accommodation were to no avail and Estate Agents were useless, they could not remember whether there was a step into anything. The information that British Rail gave out of nearby accessible stations was out of date and not comprehensive enough. I gave up. I was not going to go through the ludicrous hassle of changing my equipment for some given by another authority nor endure the waiting time for grants etc. which I know would be a minimum of 18 months.

I hate the PACT forms for applying for Fares to Work. You have to sign them personally three or four times -why one applicant signature is not enough, heaven only knows. You also have to get a signature from someone at work and from, in my case, the driver. Why do you have to do both? If you were driven to work and that is verified by the driver then why does someone else have to verify that you were actually there. It makes one feel like a thief as well as taking up a great deal of time. At least the new forms now cover four weeks instead of one.

Complaint procedures -these are a farce. If you can spare time out of a busy day to register a complaint then the bureaucracy, hypocrisy and arrogance that you face is

appalling. And in the end, more often than not, you are told that the authority concerned does not think you have a case. Which is not surprising because they would have to admit to their own incompetence if they did own up.

Travelling by airplane is another bureaucratic nightmare. Often the airline will not accept my frequent flyer card and I have to fill in, and get my doctor to fill in, that offensive form to see how offensive I am! Although my travel agent always gives complete details, when you come to check in they have no record, they argue that I have to transfer to an airport wheelchair, which I cannot do. They argue about where I should sit on the airplane making up regulations that I know do not exist. Many airports insist that you go and wait in a special section which has some stupid name like Serenity Lounge, but is in fact the most unserene area in the airport, with no drinks or snacks available. Full of unescorted children. You are treated like an idiot and not able to get to the shops. As someone whose only access to therapy is retail therapy, that is enough to put me into sever hypertension!!

I hate being asked prying medical details, when information that I am an electric wheelchair user will do perfectly well. You even have to do this on VAT exemption forms. I take a malicious pleasure in knowing that what I write down will mean absolutely nothing as even the medical profession had to invent a new form of words to describe my condition!

And talking about forms -the DLA ones are absolutely lunatic. They ask the same question several times to different people which only the disabled person themselves could answer accurately. They don't ask questions that are going to elicit the right answers. I have just been going through 50 anonymised completed forms. If the applicants had not filled in details that they had not been asked for it would have been impossible to make any reasonable assessment. And most of the form is not relevant for most people.

I wish we could be given a copy of one of our admission forms when going into hospital so that we could just hand it over to the nurses/doctors on another occasion so that we did not have to answer the same old questions over and over again. Plus the fact that I cannot remember half the stuff anyway, especially not the dates -senility!

I am sure there are many other situations I could think of but my blood pressure is getting too high, thinking about it all! I hope these ramblings are of some use to you.

## Life Scene 5

1. I was offered an accessible property in June 1997 which I readily accepted as it needed only minor alterations to be suitable for me. Then I began to set up my care package, the council had decided to begin direct payments in November of that year

but I was told I wasn't eligible as I was on middle rate care DLA, even though that decision itself had been appealed many times as I have SMA and am a full-time wheelchair user. I was TOLD, I'd have to have social services staff and go to bed at 7pm!!! I'm 24 years old now I don't want that now nor did I want it then!! I delayed my move and at times felt such despair that I thought giving in, then I contacted a family care officer from MDG who was a lifeline! she said she would appeal a decision for direct payments to only be for those on higher rate care and I was finally awarded them and moved in November with my own set of support mechanisms in place. The point however is that it didn't have to be so hard, because of an inability to see my whole life (work and social life) and accept as a twenty something 7pm for bed is unreasonable, they made me have to fight and turned what should've been one of the most exciting times of my life into a nightmare.

2. I was actually on holiday in Spain when I was offered the property I was living at home and had asked my mum to open a housing letter for me should one arrive. It did...and it said 'you must accept this property within 7 days', my mum phoned them and explained I was away for 10 days they replied no they couldn't hold it -it was my own fault I was away!! My social worker became involved (all this while I was obliviously sunning myself) and looked at the property with my mum who both agreed I would probably want it the housing officer said to my mum. 'well can you sign on her behalf, she is after all handicapped', my mum refused as did my social worker and eventually after 4 days of arguing got them to agree to hold it until I got back but I HAD to look at it the day I got back so wearily I did, however again, it shows a failure to listen...would a few days have mattered, of course not why do they have to create problems when no one else feels there is one.

3. NHS - as got to 21 years old and left paediatrics my doctor told me that although the local hospital where I had been seeing him for years was just 10 minutes away from my house, now I was an adult and going to want my yearly check-ups still with a neurologist, the neurologist at the hospital had told my paediatrician that he wasn't 'particularly interested' in SMA and that he would be reluctant to see me. This made me uncomfortable and I didn't want to see him. I have to feel comfortable with a doctor as I see it as a partnership. Luckily I was able to get referred to Oswestry where they have an excellent neuromuscular clinic, but it IS an hour and a half's drive and it is somewhat annoying when there is a perfectly good hospital on my doorstep.

4. The Council's OT dept have now got a new rule. if you do not contact your OT within 6 months of your last contact your file is closed. I can see the logic in this however when it is a long-term impairment and you will change and grow it was better the old way when you had a name to ask for when you phoned. Now you have to fill all the forms out again as if you are a new referral with no idea of the OT department at all. Disability groups were not consulted on this and in the end it makes

more work because the OT has to get to know all your history again which in many cases goes back years in terms of equipment provision.

5. My local job centre has a disability employment advisor on the 1st floor and no lift.

6. With direct payments I have aided a paper on their impact but will state to you that I feel that the paper work involved with them is silly. Incoming and outgoing is fine, but reconciliation sheets are just plain stupid and not workable, no one's bank statements add up because of when people cash the cheques but the income and spending ones do that is what should matter and we should be free to live without having to become bogged down with the paperwork of it all. It is like we are expected to have our life, working, socialising etc yet also to jump into another world of arguments and fighting for a basic right, it is hard enough being employers as well as just living without having the extra pressure.

Life Scene 6

### *Disabled Facilities Grants*

Quite a minefield in 'Shire' Counties the stages are:

- 1 Discuss situation with Health/SSD Professional who (if they are so inclined) refers you to the Community OT or you may self refer.
- 2 OT puts you on waiting list which may be up to six months.
- 3 Initial OT visit, preparation of report for Borough Surveyors.
- 4 Feasibility study and sending of report to County Social Services.
- 5 Social Services decision and recommendation which may take some time.
- 6 Preparation of scheme and costs by Borough followed by financial assessment.
- 7 If terms and scheme acceptable which include plans, consents, tenders, organising contractors etc. be put on waiting list of up to 1 year before commencement of works.

Quite a marathon.

Life Scene 7

When I started working full time last year (September 98) I had just been given the good news that my application for Independent Living Service (ILS) had been granted by Social Services.

My contribution to the package was set at £35 per week. When I received my first pay I notified the department and was told that my contribution per week would now be £80. I asked for a reason and was told that it was because my wife's wages came into the reckoning also.

So right away we are being penalised for me working. Given that I don't have a large salary, and would be expected to pay this ILS contribution and my travelling expenses contribution -with still my normal weekly commitments to keep which easily comes to well over £110 I would be putting all that effort into getting a job for no real social or financial gain.

I cut back on the hours of assistance and really only use my PAs for the real necessities. It is however quite a struggle, but it is better than nothing.

Bureaucrats need to realise if a person genuinely needs support then it should not be means tested. After all we are creating employment.

## Life Scene 8

My partner of thirteen years has limb Girdle Muscular Dystrophy. She is 33 years of age and we have managed to sustain an independent lifestyle allowing us to own and run our own home, retain my career as a school teacher (although my partner had to retire from her profession 10 years ago due to the condition) and live happily together with assistance during term time from the local Social Services. This consisted of one to one and a half hours per day from carers trained in single person manual transfer as my partner is able to weight bear but limited to 1 or 2 assisted steps only.

In February 1998 a Risk assessment was done by the Social Services who instructed the Home Care team to no longer use the manual technique of transfer as it was suddenly, it seemed, regarded by the Social Services Manual Handling Advisor as a 'lift' not a transfer.

Within a few short hours a Mobile Hoist had been brought into our home, and my partner was told (in front of carers she regarded more as friends than 'enablers') that unless the hoist was used from that moment on, Home Care could not provide a service and neither would I could any other "Care" organisation. All of this occurred when I was at work, completely oblivious to what my partner was being put through, and the trauma that met me on entering our home that evening faced with mechanical

contraptions filling the hallway and a partner in a state of utter shock and despair cannot be imagined.

It was soon established during the next 3 days of attempted use that the Hoist, although probably very useful Abattoir Technology, was completely inappropriate in the circumstances of this not unique, but rare condition. Not only was it such, but it became apparent that it was denying my partner the standing position (the opportunities to achieve this already getting fewer as the condition gradually advances) as well as her having even less control, less independence, and any scrap of dignity denied her. As the realization of what this meant to us became clearer despair and crisis followed soon after we informed the Manual Handling Advisor and Home Care that the hoist was unsuitable (to which they agreed). Their service was duly withdrawn and we were left to resolve the situation as best we could or see our lives together becoming increasingly more impossible.

I was left with no alternative then to request time off work from my employers (ironically the same local authority creating the crisis) in order that we might have this on the spot" edict i.e. a 'Lift' not a 'Transfer' overturned. This entailed, what seemed at the time, an endless round collating doctor's letters of support, reports from Muscular Dystrophy Physiotherapists, invaluable assistance and support from the Family Care Officer together with separate, in depth assessment by the Social Services Occupational Therapist (who also agreed Hoisting was unsuitable). Finally, after 8 weeks of worry, a decision was made that an alternative Care Organisation, paid for by Social Services, would provide a service without the hoist if they agreed.

This they were happy to undertake, we are pleased to say, and has continued to the present. Indeed this organisation actively encourages their clients to use any abilities they have which does seem to be enlightened thereby enriching the quality of life for its clients.

After what seemed like an eternity of worry, stress, appointments, phone calls, explanations, assessments and reports after reports in order to right this wrong, a comment made by a Social Worker describing the whole affair as a 'storm in a tea-cup' did not fill us with confidence that it is truly appreciated that so much potential devastation can be caused by decisions being made without due regard to the full facts of a case and the implications that may have on the future of those involved. For us the storm damage is still apparent. We no longer believe the powers that be have our interests at heart when we become a possible financial liability!!

Please feel free to contact us through this e-mail address but, as there were many parties involved and as we would not like to make more difficult any future dealings with the Local Authority, we would appreciate my partner's anonymity being

respected. We wish you success in your campaign and truly hope that it serves to prevent others from suffering the trauma of similar devastating "bad" decision making.

### Life Scene 9

In reply to your opening question of "Are there times when you feel 'the system' is against you?" I would say, almost always because it is! Although increasing numbers of 'right on' organisations adopt sensible language & talk of adopting an holistic approach, unfortunately the reality is very different. We are forced to be dragged through a demeaning system of community care assessment which continues to focus exclusively on a medical model approach in terms of allocating resources (due to tight eligibility criteria etc.) by focusing on what we can't do for ourselves & how many times we need to go to the toilet etc. If we do get direct payments we then have to take on loads of form filling, financial returns etc. This is obviously all on top of whatever else we do in our lives. Personally I have a very demanding job & with SMA have to stretch my energy levels to the limit as it is, without all the additional work Social Service & others give us on top of everything else.

To add insult to injury, we can then find ourselves dragged into a situation where Social Services start arguing that they should not pay for your PAs when you are at work but 'Access to Work' should pay for this. My personal view is that I don't give a damn who pays for it so long as I have the service. However I am also not prepared to find myself dragged into a situation where I am running even more administration systems (for Access to Work, ILF, Social Services etc. etc.) all with different rules & regulations!!! Aren't our lives complicated enough without the very services who are supposed to support us making them even more complicated than they were already.

It also sticks in my throat that the Government talk about empowering disabled people & getting more of us into work, yet they too show that this is mere rhetoric as they continue to support charging systems which penalise working disabled people & act as a major disincentive to work. Such charges are nothing less than a tax on disability itself & only show there does not exist any genuine commitment on the part of government to encourage disabled people to move from dependency!

Personally I feel there are so many different types of bureaucratic barriers disabled people face on a daily basis that it must all be some kind of sick joke to make our lives even more of a challenge than they were already, but I'm not laughing.

### Life Scene 10

I was very interested to read of your project regarding the unnecessary bureaucracy that those of us with SMA have to face. I can relate to all you say in the paper which was put out. I too, feel very angry about this particular issue and wish you luck in

trying to work to make some progress. It is the first time I've heard of anyone who is seriously concerned, so I would be pleased to be involved and be of any help if I possibly can be.

I thought therefore, that you might be interested to hear of my most recent experiences with "the powers that be"! I think the current example which I will tell you about is one of the most exasperating that I've had to contend with after dealing all my life (I am 51) with "suffering" (not so much with type 2 SMA) but more so with having to overcome all the frustrations of facing officious, unhelpful, narrow-mindedness, in trying to live a full and independent life.

I will try to be as concise as I can but, as I'm sure you'll understand, these problems are never short and simple. So here goes:-

My local authority opted to run a "pilot scheme" for Direct Payments after quite a lot of persuasion and enthusiasm from us residents who qualify. I was eager to be included and was accepted as one of the ten people to be guinea pigs.

I had previously for 3½ years, been on an independent living type scheme. This was originally a Crossroads Care Attendant scheme which had gone on to run a more forward-looking project, not for carers, but to provide Support Workers to individuals with disabilities. After a big struggle to get a reasonable "Care in the Community" assessment (done in the end by largely myself, guiding the social workers along, as I'm sure you'll understand!) I was accepted on to the Crossroads independent living scheme. This was funded partly by the LA and partly by ILF '93.

For the 3½ years I was on the scheme, I picked up lots of experience on Independent Living and the social model of disability etc. However, although the scheme was OK in some ways, in that one could (to a degree) interview, choose and instruct one's (fairly) regular team of Support Workers, I found it was the Manager of the scheme, not me, who had control. The local authority paid Crossroads and she, not I, was the employer. This of course had drawbacks and when any disagreements arose, I was in the powerless, "grateful" position. Even told by the Manager what was and wasn't best for me!

I was therefore ready and keen to move on to direct payments and have a good shot at employing my own PAs.

In January this year I took on one PA and found being an employer isn't nearly as difficult as I imagined, as I use a Payroll Co. and everything from this angle works reasonably well.

The major problem has been social services. Firstly, we were reassured from the start that those of us who'd already had an assessment, wouldn't have to go through another if we wanted to be included in the Direct Payment pilot. But now, six months into the scheme, this is happening.

They are, of course, denying this. They are calling it "reviewing" peoples needs. However, we are told we need to provide timed details of the "care" we need and "domestic and personal care" will need to be differentiated.

I am so angry and frustrated over this as previously, my LA has had a relatively good record on Independent Living and a lot of us with severe, physical disabilities began to believe that in our area the social model etc. were, at last understood. We felt that after much work and debate from us, with the powers that be, we were beginning to see eye to eye on being given more choice, power & independence. There was a healthy, forward-looking agreement.

Then, the new labour government/council came in with its "value for money" slogan. There have been devastating cutbacks all along aimed many times at people with disabilities and the elderly - just those of us with least access to the Council meetings, and least energy some of the time, to protest.

The cynical side of me from the start, suspected that Direct Payments would be a sneaky, cost-cutting exercise for our LA rather than encouraging independence and control over our own lives as they'd tried to persuade us it would.

Social services employed a Direct Payments support worker at the start of the pilot and all the problems began. This support worker had a very bad attitude generally. She was inefficient, rude and had no idea about disability awareness, the social model or indeed communication at all. She came into our homes and my expectation was that her main role was to advise me on using agencies or being an employer of my own PAs using Direct Payments and ILF funds. Instead of this, she adopted a managers role & declared everyone needed re-assessments. This of course threatened all of us and a few of the original ten people on the pilot pulled out altogether as a result of her tactless, heavy-handed attitude. This support worker and other social services staff have also been corresponding with ILF at Nottingham. We don't know why or what has been said behind our backs but surprise, surprise, they (ILF) now want to visit me to check things out. From the beginning the support worker asked questions about ILF and commented "you seem to have no shortage of funding". This was prior to her opinion that I should be re-assessed. When I questioned her manager about her delving into my ILF I was assured this should not have been needed. But the next week the Manager confirmed they had been negotiating with ILF as part of the pilot. After meetings with the Manager at social services over many months, myself and two other people on the scheme have been pleading how much stress we have suffered as a

result of all this. We've said now that we cannot work with this person. So the position now is that we are being made to agree that the only way to resolve this is for a formal complaint to go through from us against this worker.

God knows how long this will take.

In the meantime we are left with no support, except from peers, the whole idea of Direct Payments in my LA is on very thin ice and I feel my life and living is under even greater threat.

### Life Scene 11

My latest experience with housing seems most ridiculous. I cannot employ the assistance I need whilst living at home due to lack of space, and now the housing authority will only consider me for "disabled" accommodation (which is extremely scarce and popular) because they will not allow me to live in a block with a lift because in the case of fire they feel it would be too dangerous; never mind the fact the fire doors throughout the building would have been amply sufficient to keep the fire at bay whilst the fire brigade arrived. The most frustrating thing I found was that I wasn't even given the opportunity to make the choice as to whether or not I felt it was a reasonable risk to take.

My parents are now in the process of buying a flat to rent back to me, which we are concerned about whether we can pay housing benefit to a close relative; another bureaucratic barrier! Another issue under the heading of building a social life is what the ILF will fund: I have had problems with paying for my assistant to accompany me on train journeys, gallery and theatre visits as often I have to pay twice but cannot claim the money back, as they will not accept it is essential for me to have someone with me, although if I need to get drinks from the bar go to the loo I can't manage on my own. The attitude seems very much to be that a social life is not a necessity but a luxury. I hope these thoughts may be of some use.

### Life Scene 12

The normal day-to-day activity that I have been trying to perform is getting to and from my place of employment. The bureaucratic barrier that I have come up against is the administration of the Fares to Work (FTW) scheme. This barrier eventually led me to be interviewed under caution, arrested and interviewed by the police and to be dismissed from my job as a producer.

I have claimed FTW since 1981 at which time I travelled to work by minicab. This caused me huge stress as it meant being lifted in and out of the car by the different

drivers and also that I had to leave my powered chair at work because it could not be transported in a saloon car. There were no accessible black cabs at this time.

The job finished and I was unemployed for ten months. When I found another job I decided I could not cope with the minicabs, so I employed someone to drive me in my own vehicle. I then claimed from FTW as though I were still taking a cab and I gave the FTW money to the driver as the cheques came in. This arrangement has gone on in a more or less similar way since January this year. Over the years I got different drivers and an accessible Ford Transit van. The reason I did not clear this with PACT from the start was the small doubt I had that they would accept it as an arrangement. If they had insisted that I use cabs then I quite simply would not have been able to continue working.

I have always found the forms for FTW a considerable burden to fill in. Specifically it is required that someone signs the employers section to verify that the disabled person has been at work, which is in itself oppressive. Also it requires that the transport section is filled in and signed by someone. Who this should be is not at all obvious. Most cab companies are just not geared up or willing to deal with customer's obscure admin requirements. The journey charge is never the same twice and if the customer is paying cash, the person in the office will have no idea how much has been paid over a week or even for a Journey.

Every time the journey changes e.g. if the individual gets a new job PACT requires three quotes from cab firms for the new journey. I have changed jobs a number of times. Each time I got two quotes from taxi companies, which was difficult because cab firms are reluctant to give quotes and when they do they will always quote lower than they actually charge. I was paying my drivers a fixed amount, but I always had to ensure that I gave the lowest quote. Stupidly, when I started working for my employers in May 1995 I did not let PACT know that I had changed locations. I did this partly because I started with a three month contract, so I suspected that my contract would be ended before the admin was sorted out, but primarily because there was no difference in the amount I was paying out to the drivers, whose money I could not suddenly reduce because I was needing a slightly shorter journey. I say stupidly, but quite honestly this admin was really more than I could deal with along with doing a full time job, organising all my other access issues and trying to have a life.

I dealt with the forms by one of my drivers signing the transport section under a false name. She did not wish to be named and only did half the driving. Back at some point in the early '90s PACT asked for the transport section of the form to be stamped, so I had a stamp made, which said Portland Car Services and duly stamped the forms. The stamp made no pretence to being a genuine company. It had no company number or phone number on it. The employer section I signed with various names including that of one person who is permanently based where I worked before I went to these

employers. Again I know this was stupid but it made no material difference to the money I claimed or was entitled to and as a disabled person my energy is limited. If I had continued to work as an independent producer at my previous location there would have been no-one there with authority over me - I was the boss of my production company,- so who should have signed it, I don't know. I know of other disabled people who are the boss in their work place who also have no-one to go to in authority for this signature. One person used to sign it herself. The assumption behind these forms is that the disabled person will be doing a relatively lowly I very routine job and staying in the same job for a long time.

In March 99 the fraud investigation department of the Employment Service conducted a random investigation into PACT files. Mine was picked out. The investigator came to see me. I explained that I was not using cabs, but paying drivers. I refused to give the names of the people driving me. A few weeks later she interviewed me under caution -I still refused to give the names. I asked my employers to supply a letter stating that I had worked there since May 95, which they did. This showed I had been working, which to my mind was a crucial point. Eventually I heard that she had been to my previous place of employment and established that I did not work there. This she could have found out by asking the PACT office as I was by this time claiming FTW for getting to and from my employers and she had the letter from Personnel. She then passed the matter on to the police who eventually interviewed me and let me off with a caution.

When the investigation started had no choice but to cease my arrangement with my drivers and to start using accessible black cabs to get to work at my job. The only way to ensure that a black cab arrives on time is to book it on an account, which is a very expensive thing to do. PACT agreed to pay this cost of about £33.00 per journey. They had formerly been paying me about £11.00 per journey. The investigator knew this and also that I had made no unlawful gain through my actions, but she was simply interested in the fact that the forms were not properly filled in and wanted me prosecuted for that alone. This is what the police told me.

The end of my driving arrangement had a knock on effect on my other personal assistance needs. It meant I had to do a major recruitment exercise, which was very unsettling, hard work and expensive.

By far the worst consequence of all this was that I lost my job. The police went to my employers to establish that I worked there, in spite of having a letter stating this written by personnel in June. They informed my employers that I was being investigated for over £12,000 worth of fraud. My employers immediately suspended me, gave me a disciplinary interview and sacked me. This seems so bizarre that some might suggest they were looking for an opportunity to get rid of me. I can only say

that I know this was not the case. All of this was before had had any contact with the police.

As a postscript to my experience have just spoken to PACT about further help with FTW. I have been accepted on to a two day course which will give me the likelihood of some work in the future running training courses. I asked PACT if there were any possibility of FTW to get to the course, which will cost about £80.00 in cab fares and the answer was in the negative. I then asked about FTW to get to the courses I would eventually be running and was told that as a self employed person I would have to submit a business plan in order to show that my business is viable. All am trying to do is run a couple of maybe only one day long courses and for this they want a business plan? It seems to me that PACT, whose budget is consistently underspent is at the moment perpetrating one of the greatest bureaucratic barriers we experience as disabled people.

### Life Scene 13

At the beginning of March 1999 I received a distraught telephone call from a disabled man whom I knew from involvement in local consultation groups. His mother had died a couple of years earlier. She had been his main carer - he had lived at home with both parents. So in his early 40s, having been cared for almost exclusively by family members, he had a care package from the local authority funded by them and the ILF. His care was provided by local authority home carers in the morning and at tea-time, and he used ILF funding for agency care in the evening and at the weekend. His father still provided significant amounts of his care.

His care arrangements were in crisis, and social services had called a meeting for that day. The friend who had been supporting him could not make it, so I went along (with my PA).

He was an articulate man who knew his own body and its requirements. He was also very reasonable in the demands he made on those providing his care.

When he first started having home care the techniques he used for lifting and handling, particularly the hoist, were demonstrated by his OT, and there was also some input from the MD Group's Family Care Officer. Around the point at which I became involved, it was made clear to the man by various people that "things had to change", but he was not consulted on how they might change, nor was it explained exactly why the existing "techniques" were unacceptable and to whom. His concern and apprehension grew.

At that point, it became apparent that one of his carers, who had been trained in "new techniques" would take the lead with the other carer, and they would use the

techniques. The two carers arrived with new handling equipment. They indicated that they were going to introduce the new techniques. By that time he was already very apprehensive. It was made clear to him that he was not in control, he was not their boss. He was inevitably terrified, and “refused care”, sending the home carers away – which he could only do because he had his father to assist him.

After this incident there seems to have been a constant push to get him to agree to these new techniques. When he got in touch with me on the morning of the meeting, he was desperate for support.

The meeting, chaired by a social services manager, included the whole “team” of five home carers, the authority’s lifting and handling “specialist trainer”, the home care manager, her boss, and the team leader. The man and his father were supported by me and a representative from Carer’s National respectively.

The “specialist trainer” seemed more interested in his role as a union rep and was there, we felt, to look after the interests of his members, to the exclusion of the man’s needs and rights. He was the person who had told the home carers that they should not lift/move the man as they were doing. It was clear that he had no experience at all of people with neuromuscular impairments and that he was teaching purely generic techniques.

We fully recognised the staff health and safety issues but the man's health and safety issues were not being recognised by the meeting attendees. SMA is not a common condition. Damage can occur easily with inappropriate handling, and techniques that are fine for someone whose body matured before the onset of impairment are very often totally inappropriate for someone with this condition.

The whole atmosphere of the meeting was very confrontational and some of the issues raised, and the way they were raised, were abusive of the disabled man.

It was evident, when we arrived, that there had been discussion about the man's care before that meeting between those present, to which he was not party. This may have violated his rights to privacy, dignity and confidentiality. Furthermore, very personal additional issues about his care were sprung on him in a very large meeting. At the end of that meeting he said to me, that he was scared that "they" wanted him catheterised. Perhaps that was not what was in the minds of the meeting attendees, but that was his experience as a vulnerable adult.

We left the meeting understanding that the home carers would come the next Monday and put him through the whole of his morning and tea-time routine, with the OT there, and the "specialist trainer", so that the process could be observed and assessed. Not a very satisfactory solution but our contributor, a reasonable man, was prepared to go

through this to resolve the situation. Shortly after this, however, it became clear they had a quite different intention.

I requested that this 'assessment session' be cancelled, and wrote to the home care team leader outlining his concerns -essentially:

- two new carers were to be present at the session, which would mean it was not a true risk assessment of his existing regime
- the OT should have been familiar with SMA (his condition) so that they could advise on a change of technique, but they were not
- the presence of at least seven observers would make the process itself very difficult because of lack of space, and would actually be abusive
- there was an apparent intention to introduce some of the new techniques at the session -again it would not have been a true risk assessment
- any meeting or visit arrangements should be made with due respect to his central involvement in the process, recognising that he had other commitments and the need to prepare
- extra people should not just arrive to view the process, or discuss issues, without his prior agreement

The letter proposed that, to alleviate the distress to the man and his father, instead of the assessment session:

- agency care should be paid for by the local authority until things could be resolved, with the man himself responsible for booking the care, and thereafter he had a say in who provided care
- he would arrange a video of the process, for use in performing a true risk assessment
- any new techniques should be demonstrated on a third party before he was asked to consider using them

I pointed out that paying agency care would have been cheaper for the local authority by between £1.50 and £2 per hour. Even so, the local authority was reluctant to provide direct payments because the policy had not yet been formalised.

Finally, the letter highlighted our very significant concerns about the man's potential vulnerability to abuse from disaffected staff. He did not wish, at that stage, to make specific allegations of abuse -but some of his experience with his tea-time carers may have constituted abuse. He was in a very vulnerable position and the local authority could be liable if he were to be damaged either physically or mentally as a result of abuse.

Perhaps the use of the term abuse may seem extreme, but it is well- founded. The man was a vulnerable adult. He had a very significant level of impairment which meant that even lifting his arms had to be done with the assistance of others. He had a neuromuscular condition and, because it had been present since early childhood, he needed particular handling.

The definition of abuse used by the local authority says that abuse "may be intentional or unintentional" and that it causes harm "either temporarily or over a period of time."

I understand that he felt previously that his two tea-time carers were effectively "ganging up" on him and trying to manipulate him into accepting their view of his needs. This equates to the prohibited behaviour, in the authority's procedures, of "using personal or work power to coerce service users or carers."

The approach of two or three of the home carers delivering his home care, together with the approach of those in management who became involved with an apparent agenda of ensuring change despite his needs and wishes, conspired to cause him psychological/emotional, and potentially physical, damage. As a result of his experiences, he had to seek medical help and obtain tranquillisers.

It seems evident that abuse was taking place in this situation.

After some further exchanges, the local authority agreed to fund agency care controlled by the man himself while a re-assessment took place. They appointed two senior social workers to carry this out and they asked for assessment reports from his GP J three consultants, a physio and the OT. We insisted the MDG Family Care Officer was also involved.

Towards the end of 1999 a full set of these reports was sent to him. They added little if anything to what we had been saying all along. The social workers leading the assessment then wanted to arrange a meeting at which he was convinced, from the information he had, that they wanted to return him to the care of home carers. Direct Payments had still not been introduced. He wanted both his supporters at the meeting, so there were some problems in finding a suitable date.

Throughout this time I was aware he had a chest infection. The last time I spoke to him I felt he had just about given up. He had had a glimpse of the kind of life controlling his own care could bring, and felt he would lose this. The next thing I knew was a phone call from a mutual friend telling me he had died. He had been admitted to the local hospital, and by all accounts had not had the fight left in him to cope with inappropriate handling from nursing staff and the thought that once he came out the fight would have to continue. His funeral was held on the day the social workers had wanted to hold the meeting. Some irony in that.

## Life Scene 14

Whether my skin is changing as a consequence of the male menopause or because of my medication I don't know, but something is causing me to experience extremely uncomfortable skin rashes. Wearing a plastic spinal jacket lined with plastisote (similar to polystyrene) is the obvious cause of my dilemma -even ventilation holes, drilled all over the jacket, can't provide a total solution.

To help protect my skin from breaking and to absorb body moisture the district nurse provided Allevyn dressings. These certainly did the trick! Armed with the knowledge of this new dressing I approached the hospital orthotist to see if he would re-line my jacket with Allevyn instead of plastisote as this could prevent a lot of problems.

The orthotist asked for details of the dressing so I duly went to the hospital and dropped him one off complete with wrapper. He contacted the manufacturers who said they couldn't provide a large sheet of the material to line the jacket. The orthotist asked me if I could obtain enough patches on prescription from my GP to line the jacket. I asked him how many to which he replied "12", Previously the district nurse had told me that one 20cm x 20cm dressing cost £20. With some trepidation of the cost I put the question to my GP who initially thought he would have to clear the cost within the practice. Fortunately for me he was able to check the Allevyn dressings on his computer and found that they were in fact only some £5 each.

The GP left a prescription at the surgery which I picked up and forwarded to the local chemist who delivered it to my home.

I now have to drop off my current spinal jacket and 12 Allevyn dressings to the hospital where the orthotist will (hopefully) re-line it within a week during which time I will have to endure the previous and less comfortable jacket. If everything goes to plan I will then pick up the jacket and life should become less uncomfortable. What a palaver!!!

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*Note on the Authors*

Both Sue Maynard Campbell, BA (Hons) Solicitor, and Alice Maynard Lupton, MBA BA, are long-time members of Muscle Power! Alice is, and Sue was until recently, on its Management Committee. Both have extensive experience of researching disability issues. Sue is Managing Director of Equal Ability Limited, a disability consultancy, and Alice is Head of Disability Strategy at Railtrack plc. Both authors have undertaken this project in a voluntary capacity as members of Muscle Power!