Unequal Citizenship: The personal is political!

A Scope Disablism Audit

2008

Time to get equal

scope

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Data on non-disabled people provided by Tickbox.

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Introduction

Despite having made significant progress in developing a legislative and policy framework to support disabled people's rights, the lives of many disabled people in the UK are still characterised by lack of opportunity, marginalisation and discrimination.[1]

Scope defines disablism as: '*discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others*'. Disablism manifests itself in many different ways, from hate crime to under-representation in public political life.

Studies have consistently shown that disablism remains a pervasive part of the nation's psyche and informs many of the decisions that have a negative impact on disabled people's lives.[2]

The impact of disablism was comprehensively documented by the Government in 2005 in the Prime Minister's Strategy Unit's report entitled *Improving the Life Chances of Disabled People*.[3] In response to the report, the Government committed to taking the necessary action to ensure that:

> '*by 2025 disabled people should have the same opportunities and choices as non-disabled people and be respected and included as equal members of society*'.

Achieving this goal is all the more urgent, given the changing demographics of Britain. Advances in medical science and technology mean that many more disabled children born with complex impairments are reaching adulthood.[4] At the other end of the age spectrum people are living longer, often with age-associated impairments.

The population projections for 2031 predict that 15.3 million of the population will be over 65 (compared with 11.4 million in 2006).[5] As the proportion of the UK population living with an impairment or a long-term health condition increases, the need to secure a level playing field for this growing group of citizens becomes increasingly urgent. Though some progress has been made, the journey is by no means over.

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[1] ODI (2008) *Experiences and Expectations of Disabled People*:
http://www.officefordisability.gov.uk/research/pdfs/eedp-full-report.pdf
[2] Demos (2004) *Disablism: how to tackle the last prejudice*, London: Demos
[3] PMSU (2005) *Improving the Life Chances of Disabled People*:
http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf
[4] IPPR (2007) *Disability 2020: opportunities for the full and equal citizenship of disabled people in Britain in 2020*:
http://www.ippr.org.uk/publicationsandreports/publication.asp?id=531
[5] ONS (2007) *National Projections: UK population*:
http://www.statistics.gov.uk/cci/nugget.asp?id=1352

A Question of Numbers?

Since the mid 1990s, evidence-based policy [6] has taken pride of place in the Government's strategic approach to policy development. For organisations and academics working in the field of disability this has provided a real challenge. Whilst a plethora of statistical data exists on disabled people's lives, much of this is based on varying definitions of disability or impairment.

Furthermore, statistical measures are not representative of the disabled population as a whole. As such, it is extremely difficult to measure and evidence the effect disablism has on disabled people's lives, decisions and self-perceptions.

That said, the Office for Disability Issues (ODI) has begun a productive programme of work which aims to understand, both qualitatively and quantitatively, disabled people experiences and expectations in modern Britain. [7] This has, in part, stimulated a renewed call both inside and outside Government for baseline statistics on the demographics of disabled people living in the UK. The absence of a statistical baseline means that measuring disabled people's progress towards equality in statistical terms is extremely difficult. Where attempts have been made to use quantitative means to explore disabled people's lives and experience they have relied on unrepresentative samples and have not compared like for like.

This starting point means that inevitably official statistics can, at best, only give us an indication of disabled people's lives and, at worst, hide the very barriers which affect them. Jean Baudrillard once wrote that '*like dreams, statistics are a form of wish fulfilment*' [8] and in terms of official statistics on disabled people this is certainly the case. The Government's official statistics may *wish* to reflect disabled people's perception of their own lives and the progress they feel they are making, but in reality they do not. Until a baseline can be established this challenge remains.

So where does this leave research into disablism? As previously noted the interrogation of official statistics does not aid this pursuit. The period between now and the creation of a statistical baseline does, however, offer us a real opportunity. Rather than focusing on a representative sample we can focus on the indicative themes that arise from disabled people's self-perception of their independence, choice and control. This can then be used to identify where disabled people face the greatest barriers to being able to exercise choice and control, with a view to informing how public policy developments can address this.

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[6] C.f. Science and Technology Committee (2006) *Scientific Advice, Risk and Evidence Based Policy Making: Seventh Report of Session 2005–06*: http://www.parliament.the-stationery-office.co.uk/pa/cm200506/cmselect/cmsctech/900/900-i.pdf
[7] ODI (2008) *Experiences and Expectations of Disabled People*: http://www.officefordisability.gov.uk/research/pdfs/eedp-full-report.pdf
[8] Baudrillard, J. (1990) *Cool Memories* (Turner, C. Trans.) London: Verso p. 147

Leonard Cheshire Disability [9] has begun a series of annual reports looking at over 1000 disabled people's experiences and opinions over time. They are focusing on barriers which disabled people face in their everyday lives. These include: finance and income, employment, education, health and social services, transport and housing, citizenship and political engagement, accessing goods and services and quality of life. These reports will go some way to providing a picture of disabled people's experiences, however further work needs to be undertaken to understand the true extent of disablism in Britain.

Scope's Disablism Audit Series

This first Disablism Audit has its roots in the work Scope conducted between 2004 and 2006 attempting to understand disablism as a concept and to indicate areas of society where disablism is still rife. *Disablism*[10] and *Disablist Britain*[11] examined a selection of official statistics about disabled people's lives, looking at key indicators of equality in order to examine disabled people's progress towards equal rights and opportunities.

Scope's Disablism Audit Series, of which this report is the first, are annual reports that will provide a more robust examination of disablism in Britain today. Each year, we will ask disabled people about their own perceptions of their lives and reflect on our findings. From this we hope to construct a picture of disablism in British society and understand how this affects disabled people's day to day reality. This can then be used to explore what else is needed, in relation to policy, legislation and even social marketing, if the Government is to achieve its ambitious aim of equality by 2025.

Later reports will seek to examine the extent of our progress towards eliminating the disadvantage experienced by disabled people, both in terms of improvements over time, and relative to non-disabled citizens.

The Disablism Audit 2008 establishes the scope of subsequent annual reports. This year we have explored the key themes that underpin disabled people's experiences in a disablist Britain. The themes that have emerged from our survey provide a basis for future exploration and comparison. Whilst we cannot offer a statistical baseline for disablism, we can offer an insight into the underlying features that determine disabled people's experiences.

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[9] Leonard Cheshire Disability (2007/2008) *Disability Review:*
http://www.lcdisability.org/download.php?id=868 /
http://www.lcdisability.org/download.php?id=1139
[10] Demos (2004) *op. cit.*
[11] Scope et al (2006) *Disablist Britain: barriers to independent living for disabled people*, London: Scope

This year's report has been divided into three substantive sections, which reflect the themes underpinning disablism in modern Britain. The first of these sections, **Perceptions of Disability, Choice and Control** explores disabled people's perceptions of the level of choice and control they are able to exert over their own lives. The second section, focuses on **Relationships and Community Life**, and discusses the extent to which disabled people feel able to participate in their local community, maintain and enjoy friendships, sexual relationships and family life. Section three, **Navigating Public and Private Spheres**, considers the interaction of the public and private spheres and how this impacts on disabled people's lives. The data that informs this report is taken from four main sources – a comprehensive literature review, the results of the Scope Quiz 2008, a survey of non-disabled people commissioned by Tickbox, [12] and a small focus group of disabled people. For further details of the research methodology, please see the **Methodology** section of this report.

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[12] For more information see: http://www.tickbox.net

Section One – Perceptions of Disability, Choice and Control

Perceptions of Disability

In Britain today disabled people are over-medicalised,[13] both in public policy development and in service design. The result of this is that significant focus is placed upon impairment and only limited attention is given to addressing the societal barriers which impact upon disabled people's lives.[14] For disabled people with complex needs, this has been exasperated by an increase in the use of medical surveillance technologies.[15] These technologies have created new ways in which to reduce debates about disabled people's choice and control in society to discussions of genetics or neurological pathways.[16]

The medicalisation of disabled people's lives has proved a challenge for the UK disability rights movement.[17] Since the advent of the UK disability rights movement and the rise of disability rights academia, social research has begun to interrogate the physical and cultural barriers that underpin perceptions of disability in society.[18] Subsequently, mainly non-disabled academics have challenged this approach, calling for the 'body to be brought back into' understandings of disability.[19] This has resulted in Carol Thomas recently calling for a new approach to studying disability in social research. Thomas argues that we should aim to study disablism as our primary concern, and include impairment and impairment effects as a core part of this; thereby unifying both a focus on social barriers and health related issues.[20] Despite her call for a new approach, studies persist in focusing on one approach or the other.

The consequence of this on Government research is that it continually shifts between the two approaches. This results in a tendency to obscure the underlying disabled person's perception of choice and control in favour of health and/or management. The ODI recently undertook a comprehensive study of self-reported experiences and expectation in modern Britain.[21] The study found that over a third of disabled people said that their 'disability' had no impact on their ability to lead a full life. In contrast, 55% of respondents reported that they could not lead a full life because of their 'impairment'. It is important to note that only 1% of disabled people said they could not 'lead a

[13] Shakespeare, T. (1998) 'Choices and Rights: eugenics, genetics and disability equality', *Disability & Society*, 13(5): 665-681

[14] C.f. Swain, J., French, S. & Cameron, C. (2003) *Controversial Issues in a Disabling Society*, Berkshire: Open University Press

[15] Lauritzen, S O., & Hyden, L C. (2006). *Medical Technologies and the Life World: the social construction of normality*. London: Routledge.

[16] Lupton, D. (2003). *Medicine as Culture* (Second Edition) London: Sage.

[17] Shakespeare, T. (2006) *Disability Rights & Wrongs*, London: Routledge

[18] C.f. Swain, J., Finekstein, V., French, S. & Oliver, M. (1993) *Disabling Barriers – Enabling Environments*, London: Sage

[19] Hughes, B. & Paterson, K. (1997) 'The Social Model of Disability and the Disappearing Body: towards a sociology of impairment' *Disability & Society*, 12(3): 325 – 340

[20] Thomas, C. (2007) *Sociologies of Disability & Illness: contested ideas in disability studies and medical sociology*, Basingstoke: Palgrave Macmillan

[21] ODI (2008) *Experiences and Expectations of Disabled People*: http://www.officefordisability.gov.uk/research/pdfs/eedp-full-report.pdf

full life purely because attitudes and barriers in society prevented them from doing so'. This 1% did not mention their disability as having a role in preventing them from leading a full life.

Whilst this seems to problematise disabled people's experiences of disablism in society, we could note that the study seemed to conflate the social and medical models of disability. People cannot necessarily identify whether barriers they face in their lives are a direct result of their health need or a result of society's reaction to it. Therefore the disablist nature of modern society makes people think that the problems they encounter are related to themselves as opposed to the structures and attitudes in society.

The ODI study did not attempt to standardise or understand respondents' differing interpretations of the terms 'disability' and 'impairment' and as such could not standardise the respondents' understandings of the concepts used in the survey. As a result, a high number of disabled respondents reported their lives in relation to immediate health needs. This is demonstrated in the report's observation that only 6% of disabled people consciously articulated the social model of disability. This observation was reflected in the qualitative findings of the research. The report notes that in the majority of the qualitative responses, where respondents felt they were unable to 'lead a full life' they tended to attribute this to their impairment-related issues, rather than to societal barriers and attitudes. The ODI report reflects the findings of previous Government research conducted in 2001, *Disabled for Life.*[22] When comparing the two studies it seems that awareness of social barriers is decreasing. More disabled people in 2007 (36%) reported that they felt that their disability had no impact on their 'ability to lead a full life' than had been the case in 2001 (31%).[23]

Interestingly, the ODI reports that in cases where respondents were active members of campaigning groups, they were more likely to be au fait with the social model of disability. This perhaps is not surprising as individuals involved in the disability rights movement will have more exposure to narratives of disablism and understand how this affects their everyday lives.

Whilst there is a vibrant disabled rights movement in the UK, we do know that very few disabled people have an opportunity to participate in it fully.[24]

Aspects of the disability rights movement are overly separatist, antagonistic and do not appeal to many disabled people. However, engagement with activists is one of the few ways in which people are introduced to the social model and realise their rights. The limited access and attraction to the

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[22] Grewal, I., Joy, S., Lewis, J., Swales, K. & Woodfield, K. (2002) Disabled for Life?: attitudes towards, and experiences of, disability in Britain (DWP Research Report No. 148): http://www.dwp.gov.uk/asd/asd5/rrep173.pdf
[23] The ODI report compares the two statistics despite the fact that both the sample and the definitions used are not comparable.
[24] Disability LIB Alliance (2008) *Thriving or Surviving: Challenges and opportunities for Disabled People's Organisations in the 21st Century*: http://www.disabilitylib.org.uk/assets/pdf/c28897-disability-lib-report.pdf

disability rights movement leads to disabled people not being exposed to the knowledge and networks that could provide them with an understanding of the social model of disability and empower them to have more choice and control in their lives.

1,320 disabled adults responded to the Scope Quiz, of these 38% of respondents found it difficult to get the information they need to make informed choices about their life. When one considers that the respondents to our survey self-identified as disabled people and are therefore more likely to be aware of organisations, services or disability-focused publications that might be able to provide information and advice, this represents the tip of the iceberg. This is a worrying trend given that, the ODI report suggests that an awareness of how societal and impairment-related issues interact together in daily life is decreasing in preference for accounts of impairment and health-specific related issues. The report states that whereas 11% of disabled people in 2001 reported their 'disability and attitudes and barriers in society that prevent them from leading a full life', this had more than halved to 5% by 2007. [25]

The suggestion that impairment-specific or health-related issues are the most prominent barrier for disabled people's full participation in society conflicts with other ODI programmes of work which look at how people's health, life opportunities and financial savings could be increased by implementing a more social model of independent living.[26] That said, the concluding summary of the 2008 ODI study does identify that:

> '*Many of the barriers described in the research are consistent with the social model, and this, along with other evidence of inequality, indicates that there may still be some way to go until disabled people achieve substantive equality in Britain.*'

This contradiction seems to indicate an acknowledgement that while disabled people's perceptions of disadvantage are still strongly influenced by a medicalised view of disability, in reality the barriers people identify can frequently be attributed to social and cultural barriers rather than an individual's impairment.

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[25] The ODI report compares the two statistics despite the fact that both the sample and the definitions used are not comparable.
[26] C.f. Heywood, F. & Turner, L. (2007) *Better Outcomes, Lower Costs: implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence*:
http://www.officefordisability.gov.uk/docs/better_outcomes_report.pdf
Hurstfield, J., Parashar, U. & Schofield, K. (2007) *The Costs and Benefits of Independent Living*: http://www.officefordisability.gov.uk/docs/independent_living_report.pdf

Perceptions of Choice and Control

So where does this leave the question of choice and control that underpins the social change that the disability rights movement is advocating for? In a political climate where personalisation has become the new panacea to solving the social care crisis,[27] more and more emphasis is being placed upon allowing individuals to manage their own finances, resources and as such exercise greater choice and control over their everyday lives. From the leisure activities they engage in, to the care services they purchase, this increased devolution of power to the individual, has, at least theoretically, led to more disabled people having greater choice and control over their day to day lives.

In our survey of 1,320 disabled people and 1000 non-disabled people we asked people how much choice and control they felt they had in their lives. On the surface, our findings show that the majority of people felt they had at least some choice and control: 83% of disabled people and 92% of non-disabled people. This does illustrate a difference of 9% between disabled people and non-disabled people's self-perception of choice and control in their lives.

How much choice and control do you have over what happens in your life?
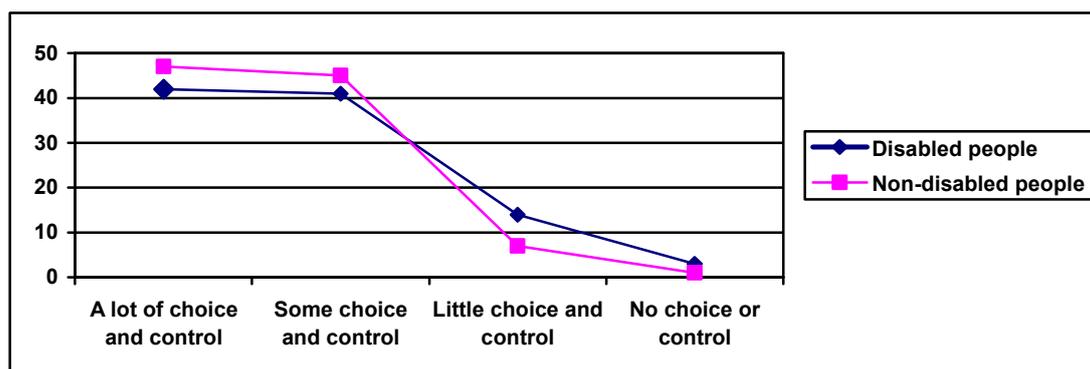
This result may seem at first glance to be surprising given the significant difference in disabled people's life opportunities than those of non-disabled.[28]

However, as we have seen previously, disabled people seem to give more weight to impairment-specific or health-related issues than societal barriers. Despite this the ODI research found that 55% of their respondents said that they 'could not lead a full life due to their disability'.[29] This again distorts the very real consequences that disablism has on disabled people's self perception.

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[27] Scope, Age Concern & Mencap (2008) *Rights not write off!: What disabled people and older people want from social care reform*:
http://www.timetogetequal.org.uk/core/core_picker/download.asp?id=420
[28] PMSU (2005) *op. cit.*
[29] ODI (2008) *op. cit.*

With very few disabled people having access to alternative, more empowering narratives about their lives, they are more likely to think that their level of choice and control is high, irrespective of how much restriction is placed upon it. This sentiment is reflected when we contrast the initial question of choice and control with the question we asked participants about their future quality of life. When imagining their future, the wider disparity between disabled and non-disabled people becomes apparent.

By comparing disabled and non-disabled people's responses to the question of future quality of life, we get almost a mirror image of self-perceptions. As the graph below illustrates, the response from disabled people was skewed towards a negative self-perception (23% positive to 77% negative), whereas non-disabled people's responses displayed the opposite trend (73% positive to 27% negative). Similarly, our survey found that only 54% of disabled people thought about their future and planned their life ahead, compared to 81% of non-disabled people. This reflects a pattern across all survey responses from disabled people - 45% of responses to questions had a negative majority (over 50% of respondents gave negative answers).

What do you think your quality of life will be like in five years?
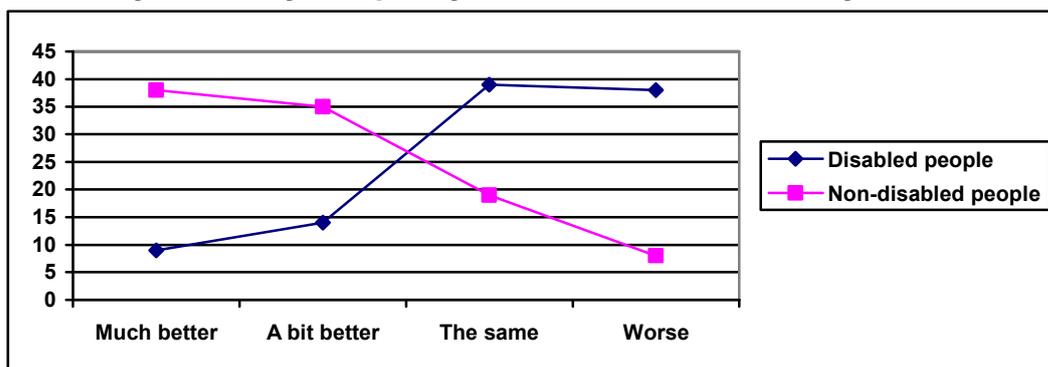
An interesting trend emerges from our data as the exploration of choice and control broadens to explore disabled people's views, opinions and level of self confidence.

We know that a key aspect of exercising choice and control is an individual's level of self confidence.[30] If an individual is more confident they will take more risks and as a consequence be able to have new experiences and participate in a wider range of activities. Only 29% of disabled respondents to our survey felt they were very confident in dealing with day to day life. In contrast, a quarter of respondents reported that they had little or no confidence in dealing with day to day activities.

Disabled people's difficulty in exercising choice and control becomes even more apparent when these statistics are coupled with those about views and opinions. In our survey over a third of disabled respondents found it difficult to get their views and opinions listened to. Similarly when we asked disabled

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[30] C.f. French, S. (1994) *On Equal Terms: working with disabled people*, Oxford: Elsevier Health Sciences

people how easy it was to get the information they need to make informed choices, 38% reported that they felt it was difficult. This is in stark contrast to just 8% of non-disabled people we asked. When we look at the group who felt they could get access to appropriate information only rarely or never, this only represented 1% of non-disabled people, but a worrying 11% of disabled people.

How easy is it to get the information you need to make informed choices?
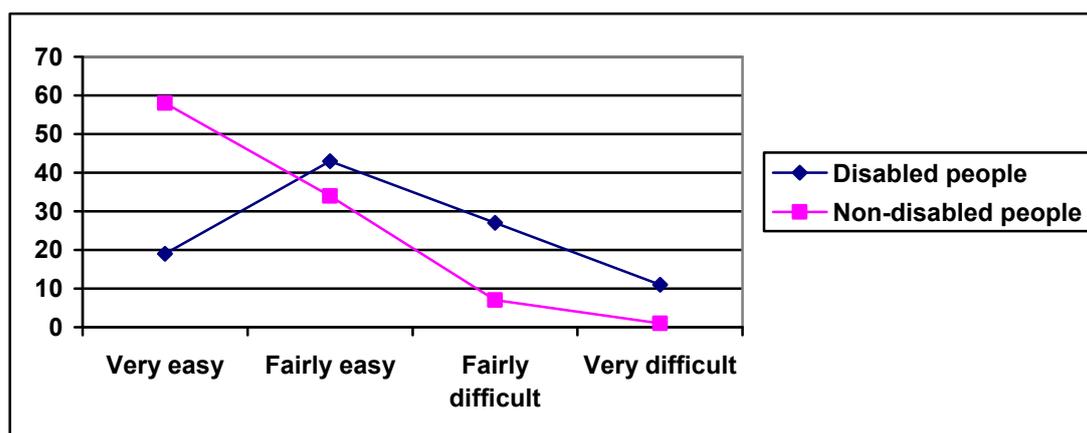
That most disabled people report that it is only *fairly easy* to get the information they need to make informed choices (compared to the majority of non-disabled people who find it *very easy)* illustrates the effect that underlying disablism within society has on disabled people's realisation of choice and control. Disabled people often need more information than non-disabled people, due to the complexity of entitlement to services, financial management and employment services. Fundamentally, if you cannot get others to understand your point of view, respect your opinions or get the information you need to make decisions, it is highly likely that you will become marginalised.[31]

Our survey findings seem to demonstrate that there is a disjuncture between disabled people's perception of how much choice and control they have over their daily lives and the practical realisation of that choice and control. We could speculate that this is because disabled people have very limited experience of what actually constitutes *choice and control*. They often do not have exposure to the forms of choice and control that would give them most freedom and the best quality of life, rather their position in a disablist society means that they are offered restricted opportunities to realise choice and control in their lives. Many disabled people told us that they felt that in most circumstances they were only offered second-best opportunities.

The relevance of this to understanding disablism is that disabled people's ability to exercise choice and control operates in confined conditions. When disabled people are able to exercise choice and control, they are only doing

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[31] Morris, J. (1991) *Pride Against Prejudice: a personal politics of disability*, London: Women's Press.

so within a restrictive context. This analysis is supported in part through our survey results, in which disabled people reported high levels of positive self-perception in relation to choice and control in their lives. However, as further exploration is undertaken it becomes evident that this self-perception of choice and control is only operating in a restricted manner. In these confined conditions a disabled person's confidence, voice and respect is restricted. This stands in sharp contrast to the ethos of the Government's Independent Living Strategy which was published last year. In the foreword of that strategy the Prime Minister writes that:

> '*[The Government's] vision for Britain is of a society where all citizens are respected and included as equal members... For many disabled people that vision can seem far removed from the reality of their lives. But the lives of some have been transformed by having choice and control over the support they need. We are committed to extending such self-determination to all disabled people.*' [32]

Our results show disabled people as being far from *respected* and *equal* citizens in Britain. They find it difficult to have their voices heard, to have their opinions respected and have little confidence to exercise choice and control in their daily lives. When they have the opportunity to exercise choice and control it is in a restricted manner, which in many cases means that their needs are not met. We need to work to address these confined conditions so that disabled people demand more effective and better services. In doing so, Britain needs to develop and reinforce a wider understanding of the social model of disability as the lens through which disabled people can understand their lives.

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[32] ODI (2008) *Independent Living: A cross-government strategy about independent living for disabled people*: http://www.officefordisability.gov.uk/docs/ilr-executive-report.pdf

Section Two – Relationships and Community Life

So far, this report has observed that disabled people's choice and control operates within restricted conditions. This means that disabled people have fewer opportunities to exercise choice and control in their everyday lives. In the last section we looked at disabled people's perceptions of choice and control. The findings showed that despite disabled people's perception that they had a lot of choice and control, their responses to other questions revealed that in reality this was much more limited. Section Two aims to build upon this by looking closer at how these restricted conditions affect disabled people's opportunities to participate in their local community, build friendships, have sexual relationships and create a family life.

Community Life

We know that disabled people have fewer opportunities to participate in their local communities due to the systemic inaccessibility of both the physical and cultural environments. Many of the socio-geographical structures of local communities are not inclusive and unwittingly exclude disabled people.[33] Our own survey supports this - 60% of respondents told us that they could not access community activities.

Similarly disabled people are restricted as to where they can live. A shortage of accessible homes [34] and inaccessible or unreliable public transport services[35] limit access to leisure and community activities. Despite the importance of having choice and control over where you live, many disabled people and their families are forced to move into new communities in order to access suitable housing.[36] As we can see, disabled people's opportunities to participate in their local community are often very constrained.

This is exacerbated by the fact that disabled people are at greater risk of living in poverty.[37] There are currently just over two million disabled parents in the UK and around half of these are also workless, accounting for one in three out-of-work disabled adults.[38] Low incomes mean disabled people are more likely to live in social housing or in areas of greater social and economic deprivation.[39]

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[33] Gleeson, B J. (1996) 'A Geography for Disabled People?', *Transactions of the Institute Of British Geographers* 21: 387 – 396
Gleeson, B. (2001) 'Disability and the Open City' *Urban Studies* 38(2): 251-265
[34] For more information see: http://www.lifetimehomes.org.uk
[35] Webster, L. & Shah, S. (2008) *Into the Unknown: Disabled people's experiences of public Transport*: http://www.lcdisability.org/download.php?id=1006
[36] C.f. Butt, J & Dhaliwal, S. (2005) Different Paths, Challenging Services: A study of the housing experiences of black and minority ethnic disabled and D/deaf people: http://www.differentpaths.org.uk/downloads/research_report.pdf
[37] Leonard Cheshire Disability (2008) *Disability Poverty in the UK*: http://www.lcdisability.org/download.php?id=899
[38] Preston, G. (2006) 'Living With Disability: a message from disabled parents' in Preston, G. (ed) *A Route out of Poverty?: Disabled people, work and welfare reform*: http://www.cpag.org.uk/publications/extracts/route_out_of_poverty_4.pdf
[39] Kemp, P., Bradshaw, J. Dornan, P., Finch, N. & Mayhew, E. (2004) *Routes out of poverty: a research review*: http://www.jrf.org.uk/bookshop/eBooks/1859352316.pdf

Leonard Cheshire's *Disability Review 2008* supports this. 54% of their respondents had an income of less than £300 a week, compared to national figures which show that 29% of UK households overall are living on less than £300 per week.[40] Our own survey of disabled people found that only approximately a third of people had enough money to buy the things they needed. Not having the financial or physical means to access their local communities means that disabled people are more likely to be unable to participate in community life. Our survey found that 20% of disabled people did not feel safe and secure at home and in their local community. Other research we have conducted has illustrated how, in extreme cases, this marginalisation and ignorance results in the victimisation of disabled people and sometimes in the perpetration of a disability hate crime.[41]

This marginalisation is further illustrated by the extent to which disabled people are able to participate in determining what happens in their local area and who should represent them on local issues. At the last General Election (2005), Scope's Polls Apart[42] research, which covered 81% of constituencies in the UK, found that 68% of all polling stations surveyed had one or more serious access barrier. This was an improvement of just 1% from when we had surveyed them in 2001. In addition, 63% of postal voting systems failed our basic access test, meaning that many disabled people did not have access to an accessible method of voting for their local member of parliament. Similarly, statistics from the Councillors' Census show that the numbers of councillors identifying as disabled people has reduced from 12.9% in 2001 to 12.4% in 2004 to 10.9% in 2006.

Evans, S (2007) *Disability, Skills & work: Raising our ambitions*:
http://www.smf.co.uk/assets/files/publications/Disability,%20skills%20and%20work.pdf
[40] Leonard Cheshire Disability (2008) *Disability Review*:
http://www.lcdisability.org/download.php?id=1139
See also http://www.lcdisability.org/download.php?id=891
[41] DN, Scope, UKDPC (2008) *Getting Away With Murder: Disabled people's experiences of hate crime in the UK*:
http://www.timetogetequal.org.uk/core/core_picker/download.asp?id=405
See also: http://www.timetogetequal.org.uk/hatecrime
[42] Scott, R. & Crooks, A. (2005) *Polls Apart 4: Campaigning for accessible democracy*:
http://www.pollsapart.org.uk/2005/docs/Polls%20Apart%20report%20final.pdf

Building Friendships and Relationships

As we have seen, many disabled people remain marginalised from their local communities. This is despite participation in local communities, and independent living being present in articles of both the *Universal Declaration of Human Rights* (Article 27) [43] and the *UN Convention on the Rights of Persons with Disabilities* (Article 19).[44] Many disabled children and young people are educated separately from non-disabled children which restricts their ability to interact with their peers and establish friendships outside their immediate peer group.[45] This is acute in residential specialist settings.[46] This is then replicated in adulthood where disabled people, both in and out of residential settings, are constrained in their ability to build friendships away from their immediate peer group or family.[47] Many of these settings have restrictions on activities or curfews and as such disabled people living there do not have the range of opportunities to meet new people and make new friendships.[48]

The Government has recognised this in their comprehensive analysis of the situation of disabled people in Britain in 2005.[49] At the time the Government suggested that local services could lead the way to disabled people having more opportunities to build friendships and relationships in the local community. This sentiment is reflected in the Government's 2007 document *Valuing People Now* [50] which calls for local commissioners and local service providers to do more to promote disabled people's access to personal relationships. *Valuing People Now* recognises that friendships and relationships of a personal and sexual nature are important to people with learning difficulties and cites a national survey which showed that 31% of disabled people had no friends and 5% of people had neither contact with friends nor with their family. The report then goes on to list a range of societal barriers including professional decisions about service delivery that do not take into account existing relationships, friendship or familial set ups; services getting the balance wrong between protecting vulnerable people and helping people have a life, through positive risk-taking; and attitudinal barriers relating to disabled people's sexuality.

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[43] UN (1948) *The Universal Declaration of Human Rights*: http://www.un.org/Overview/rights.html

[44] UN (2008) *The United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD): http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

[45] Barton, L. & Armstrong, F. (2003) 'Disability, Education & Inclusion: Cross-cultural issues and dilemmas' in Albrecht, G L., Seelman, K D. & Bury, M. (eds) *Handbook of Disability Studies*, London: Sage

[46] Morris, J. (2001) 'Social Exclusion and Young Disabled People with High levels of Support Needs' *Critical Social Policy* 19(3): 527–545

[47] Barnes, C. & Mercer, G. (2005) 'Disability, Work, and Welfare: challenging the social exclusion of disabled people' *Work, Employment & Society* 19(3): 527–545

[48] C.f. http://www.mencap.org.uk/displaypagedoc.asp?id=9438

[49] PMSU (2005) *Improving the Life Chances of Disabled People*: http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf

[50] DH (2007) *Valuing People Now: From Progress to Transformation*: http://www.dh.gov.uk/en/Consultations/LiveConsultations/DH_081014?IdcService=GET_FILE&dID=156824&Rendition=Web

As we have noted previously the Government has suggested that this area is not the responsibility of national Government. As the former Minister for Care Services (Ivan Lewis MP) in his evidence to the Joint Committee on Human Rights remarked '[the State] *does not have a duty to provide people who are lonely with a friend*'.[51] Unfortunately what the Government has acknowledged in their report, but fail to take account of in their policy-making, is that local commissioners and services play a key role in perpetuating the institutionalised disablism that systemically prevents disabled people from accessing their local community and building friendships and/or relationships. The message from the Government here is contradictory. On one hand it acknowledges the failure of local commissioners and service providers to understand and support disabled people's rights to relationships, yet with the other recommends it is they who deliver this step change at a local level.

In reality this means that the experiences of disabled people on the ground have not dramatically changed. Worryingly our survey found that only 27% of respondents get to see people that they enjoy spending time with very regularly. Given this, it is not surprising that 58% of disabled people we asked told us that they felt they had low levels of fun in their everyday life, compared to under half this number of non-disabled people (24%). Despite this, half of respondents said they felt happy and content at least most of the time – compared to 78% of non-disabled people.

Disabled people have less fun and feel less happy because of how they experience their restricted choice and control in their everyday lives. If disabled people cannot exercise choice and control over their lives, a natural consequence is to end up not spending time with people you enjoy spending time with. Not having fun and not feeling content is part and parcel of not being able to determine for yourself the peers you interact with and the activities you engage in.

We consider successful relationships and friendships to be based on trust and respect.[52] Despite this, a quarter of disabled respondents reported that people who know them give them little respect and do not treat them well. If we look at the graph below we can see that disabled people and non-disabled people's self-perception are mirror opposites: as non-disabled people's self-perception of respect increases; disabled people's decreases at a similar rate.

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[51] Joint Committee on Human Rights (2008) *A Life Like Any Other?: Human rights of adults with learning disabilities (Seventh Report of Session 2007–08, Volume I)*: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf
[52] Bell, S. & Coleman, S. (1999) 'The Anthropology of Friendship: Enduring themes and future possibilities' in Bell, S. & Coleman, S. (eds) *The Anthropology of Friendship*, London: Berg

How many of the people you know do you think respect you and treat you well?
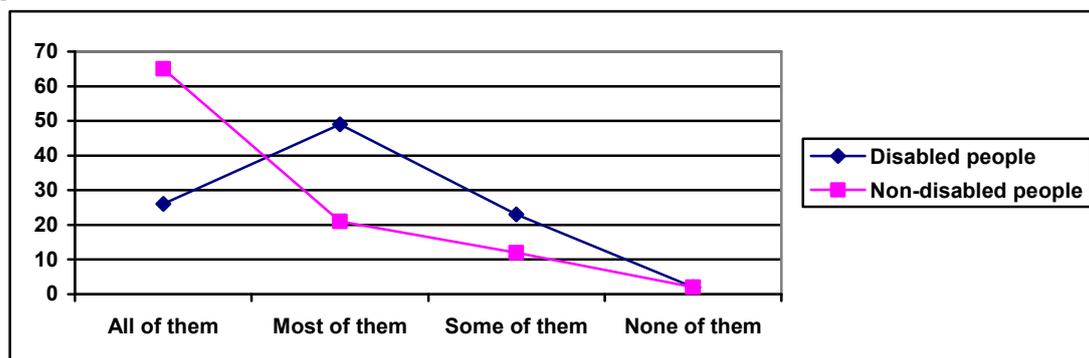
As we have seen, many disabled people are not spending time with people who respect them and that they have fun with. Furthermore they often have to rely on non-disabled people to access friendship activities. This situation becomes even more problematic when disabled people want to explore their sexualities. An important aspect of intimate human relationships is the opportunity to explore one's sexuality and engage in sexual activity, however many disabled people do not have opportunities to explore this aspect of their lives. Paul Anderson & Rob Kitchin [53] argue that disabled people are commonly understood to be asexual, uninterested in sex or unable to take part in sexual activity. They furthermore note that when disabled people's sexual activity is represented in popular culture or in the media it is seen as 'monstrous' and that the individual is unable to control their sexual drives and feelings. It is these cultural representations which become embedded in the design of services, information, advocacy and the experiences of disabled people's sexualities.[54]

Tom Shakespeare[55] attempts to explain why disabled people's sexuality has remained a marginalised issue in current debates. One of the underlying barriers is that of prioritisation, as Shakespeare notes: '*ending poverty and social exclusion comes higher up the list of needs, than campaigning for a good fuck, and for access to clubs and pubs*'. Furthermore, he suggests that sexuality has for a long time been an area of distress, exclusion and self-doubt for disabled people and that it was easier for the disability rights movement to not consider it and concentrate on other areas of exclusion from society. As such, disabled people's sexuality became problematic, taboo and often pathologised. All these are underpinned by disablist assumptions about an inability of disabled people to engage in sexual relationships and/or activities.[56]

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[53] Anderson, P. & Kitchin, R. (2000) 'Disability, Space & Sexuality: access to family planning services' *Social Science & Medicine* 51(8): 1163-1173
[54] ibid
[55] Shakespeare, T. (2000) 'Disabled Sexuality: toward rights and recognition' *Sexuality & Disability* 18(3): 159-166
[56] Shakespeare, T., Gillespie-Self, K. & Davies, D. (1997) *The Sexual Politics of Disability*, London: Cassell
Shakespeare, T. (2000) 'Disabled Sexuality: Towards rights and recognition' *Sexuality & Disability* 18(3): 159-166

As previously demonstrated, this is exacerbated by disabled people's marginalised position in their local community and in many cases their inability to have their voices heard by people who respect them.

This disablist notion of a problematic disabled sexuality becomes embedded in the everyday realities of disabled people. Heyman and Huckle's [57] study of adults with learning difficulties posits that most parents and carers of disabled adults perceive sexual relationships to be unacceptably dangerous. Parents and carers, it is argued, do not attempt to understand a disabled adult's sexuality, but rather see it as hazardous and attempt to limit the risk of it occurring by restricting disabled people's lives. The extent to which parents or carers restricted disabled people's lives was based on the level of risk they attached to sexual activity, in relation to the adult's needs. The study clearly demonstrated that disablist attitudes toward sex result in disabled people not being express their sexuality appropriately, and is not acknowledged or recognised by family or professionals caring for them. What is interesting about the approaches that these services and parents took is that they did not consider the impact sexual pleasure can have on quality of life.[58] As such, disabled people's sexuality was once again reduced to bodily, behavioural and emotional functioning.

> '*Our carer says we can't kiss (me and my girlfriend). She says 'we've got to draw the line somewhere*'[59]

In our written evidence to the Government's Joint Committee on Human Rights'[60] inquiry into adults with learning difficulties, Scope highlighted how this impacted on disabled people's lives. We told the Committee that people with a learning difficulty, particularly those with complex needs, are often prevented from entering into a relationship because others believe they are unable to make an informed choice about sexual activity. In some care homes relationships are completely banned whilst in others it is assumed that all disabled people are asexual. For disabled people who identify as homosexual the opportunity to express their sexuality or have a same-sex relationship can be even more difficult. This is primarily due to the heterosexist assumptions of both services and the disability rights movement as a whole.[61]

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[57] Heyman, B. & Huckle, S. (1995) 'Sexuality as a Perceived Hazard in the Lives of Adults with Learning Difficulties' *Disability & Society* 10(2): 139-155

[58] Tepper, M S. (2000) 'Sexuality and Disability: The missing discourse of pleasure', *Sexuality & Disability* 18(4): 283-290

[59] Joint Committee on Human Rights (2008) *A Life Like Any Other?: Human rights of adults with Learning Disabilities (Seventh Report of Session 2007–08, Volume I)*: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

[60] Joint Committee on Human Rights (2008) *A Life Like Any Other?: Human rights of adults with Learning Disabilities (Seventh Report of Session 2007–08, Volume II)*: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40ii.pdf

[61] Tremain, S. (2000) 'Queering Disabled Sexuality Studies', *Sexuality & Disability* 18(4): 291-299

McRuer, R. (2006) *Crip Theory: Cultural signs of queerness and disability*, London: New York University Press

Sandahl, C. (2003) 'Queering the Crip or Cripping the Queer?: Intersections of Queer and Crip identities in solo autobiographical performance' *GLQ: A Journal of Lesbian and Gay Studies* 9(1-2): 25-56

We further argued that having the appropriate support to make these kinds of personal decisions is vital to ensure a person's rights and choices are not restricted. One study found that 74% of their respondents felt they had generally received poor quality information about sex, which had left them ill-prepared for embarking on a sexual relationship.[62]

> **Case Study 1**
> *Jane is in her 30s and has learning difficulties. She lives with both her parents in a small community.*
>
> *She attends local authority day services on a number of days in the week. Over a period of time she has become emotionally and sexually attracted to another person at the centre. The feelings are returned and they have formed a close relationship. They have known each other for some considerable period of time. Jane expressed her thoughts to both her social worker and personal assistants. An advocate was called in to support Jane in thinking through the consequences of her wishes, which were to live with her boyfriend in supported accommodation. Jane's parents were adamant that Jane did not understand what she wanted and that she should remain living at home and not get further involved with her boyfriend. After a number of sessions the advocate confirmed the consistency of Jane's views. The advocate represented them to the parents. The parents would not condone Jane leaving home and applied a great deal of pressure on Jane to 'change her mind'. This case ended with Jane remaining at home.*

Here we see disabled people's sexuality operating in a restricted context and becomes entrenched in a culture of risk[63] and is regulated by non-disabled people's assumptions about appropriateness. This trend becomes more pronounced when disabled people are asked directly about their own self-reported experiences of sexual activity and sexuality. In 2005 Disability Now magazine published the findings of its *Time to Talk Sex* survey. With more than 1,100 respondents, it was one of the UK's largest surveys of disabled people's sexuality. The *Time to Talk Sex* survey examined the sexual experiences and attitudes of disabled people in the UK. It looked at disabled people's sexual history, their attitudes to sex, their impairment and their experiences of sexual activity. It found that over 93% of those who had no one to talk to about their sexuality had poor body image and sexual self-esteem: a trend reflected in previous studies.[64]

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[62] Banim, M., Guy, A. & Tasker, P. (1999) 'Trapped in Risky Behaviour: Empowerment, disabled people and sexual health' *Health, Risk & Society* 1(2): 209-221
[63] Lupton, D. (1999) *Risk*, London: Routledge
[64] C.f. Taleporos, G. & McCabe, M P. (2001) 'Physical Disability and Sexual Esteem' *Sexuality and Disability* 19(2): 131-148

A study of disabled people's sexuality undertaken by Leonard Cheshire Disability[65] in 2008 found that nearly half (46%) of single disabled respondents said they were not optimistic about finding the right partner. This is not surprising given that around a third of respondents found it difficult to meet potential partners. Despite this many disabled people see sex as a positive expression within the context of a loving relationship, and see it as an important facet of independence from family and professionals.[66]

Our own survey has found that a shocking 64% of disabled respondents, compared to just 34% of non-disabled respondents, do not have the opportunity to explore their sexuality or have a sexual partner or partners. In fact, 3% of our respondents did not know what their sexual preference was. This perhaps is not a great shock given our findings on the low numbers of disabled people who have the opportunity to spend time with people whose company they enjoy and have fun with. Following this, the realisation of sexuality for many people is based on the ability to do things spontaneously. However, our survey found that only 43% of disabled respondents could do things spontaneously in their day to day lives, compared to 72% of non-disabled people.

How easy is it for you to do things spontaneously (e.g. go out for a meal, invite friends round, go shopping)?
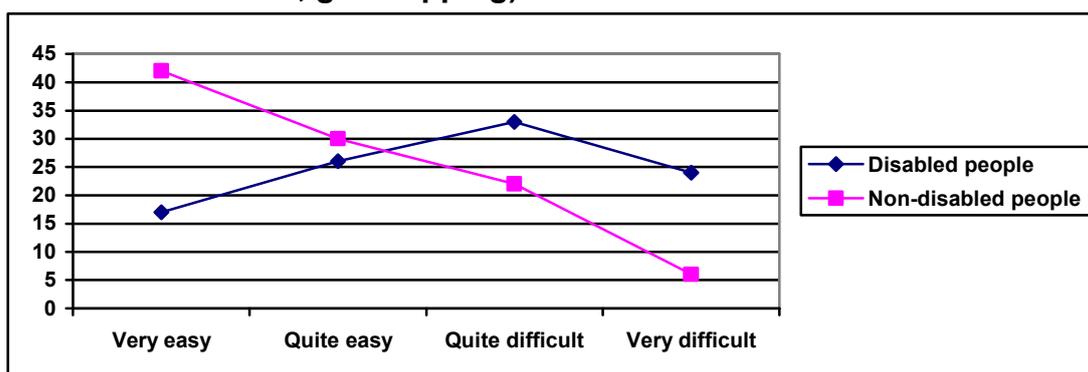
Thus, the restricted situations that disabled people occupy do not allow for the flexibility needed to achieve this spontaneity. As such, sexual interaction cannot just occur, but rather takes planning and in some instances negotiation with service staff.

> **Case Study 2**
> Sarah is in her 60s and now lives independently in the West Midlands.
>
> 'I had absolutely no control over when I got up in the morning, when I went to bed, what time I ate, when I had a shower etc. In fact, because I had such little support I was forced into having a

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[65] Laxton, C. & Goldsworthy, A. (2008) *Up Close and Personal: A report into disabled and non disabled people's attitudes and experiences of relationships in the UK*: http://www.lcdisability.org/?lid=7699

[66] ibid

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hysterectomy. In any one week there could be as many as twelve people in my home. Because the rota was prepared a month in advance I was unable to have any relationships. I was so discriminated against in every area of my life that on one occasion I put a large notice on my door saying "No home carer required – overnight visitor... I often had to entertain visitors in my nightwear because staff would come to undress me at seven in the evening. If a Monday involved a Bank Holiday then I had no shower – sometimes for as long as three weeks.'

When disabled people want to develop these relationships further they can face considerable opposition - this is particularly the case for disabled people living in residential settings. Few residential services provide accommodation for couples and it is still not uncommon for older married couples who move into residential care to be separated from each other.

> ### Case Study 3
> *Mr Lee gave oral evidence to the Joint Committee on Human Rights during their inquiry into people with learning difficulties.*
>
> *'People are stopped from having boyfriends and girlfriends for a number of reasons, all to do with us being regarded as not as good or as capable as other people. Some people want us to stop breeding in line with eugenics. Some people do not see us as adults and therefore as not capable of relationships. Some people think we will not be able to look after children. My ex-wife was told by her parents that sex was wrong because she had a learning difficulty and they had her sterilised. One of the factors in the breakdown of our marriage was the fact that we could not have children, which we desperately wanted. Society needs to realise that we are adults, with the rights of adults.'*[67]

This is indicative of many disabled people's experiences of sexuality, despite the fact that self-determination of one's body or life is a core underlying principle of the Human Rights Act.[68]

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[67] Joint Committee on Human Rights (2008) *A Life Like Any Other? Human rights of adults with Learning Disabilities (Seventh Report of Session 2007–08, Volume II):* http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40ii.pdf
[68] Human Rights Act [1998] (c. 42): http://www.opsi.gov.uk/ACTS/acts1998/ukpga_19980042_en_1

Having Children and Raising a Family

Despite the right to bodily integrity being a fundamental aspect of human rights, it is still not uncommon for disabled children and young people to have their fertility restricted by medical professionals. It has been argued by clinicians that some disabled young people do not have the mental capacity to understand what it is like to have children and as such restriction of their fertility is not problematic. In extreme cases this is used to either restrict the growth[69] and physical maturation of the child or sterilise them.[70] This results in a forced intervention in the psychological, emotional and physiological journey towards adulthood.[71] As Tom Shakespeare highlights:

> *'To conclude that [disabled] children… have no personal interest in being fertile or reaching the stature and body shape of other adult women is to… fail to appreciate the symbolic significance of being an adult woman for the way in which disabled people are treated. Even if a person is never able to experience her sexuality or adulthood or even become aware of it, the fact that she has those attributes may be significant for the way that other people experience her, and more importantly, treat her.'* [72]

In 2007 one particular case came to international prominence. In the USA, parents of a nine year old disabled young girl (Ashley X) were seeking non-therapeutic surgical intervention to restrict her growth and maturation so she would remain like a child and be easier to care for. Her parent's wishes were supported by their medical advisers and, without approval from the courts, Ashley was given a hysterectomy, had her breast buds removed and received hormone treatment to restrict her growth. It appears that the doctors and the child's parents acted unlawfully by not seeking approval from a court for this intervention, yet to date no legal action has been taken against any of the parties involved.

The media's coverage of this case generated numerous other accounts of sterilisation or intended sterilisation of disabled children and young people in the UK.[73] Scope is highly concerned that without tighter legal safeguards, medical interventions similar to those in the Ashley X case could occur in Britain.

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[69] Schmidt, E B. (2007) 'Making Someone Child-Sized Forever?: Ethical considerations in inhibiting the growth of a developmentally disabled child' *Clinical Ethics* 2(1): 46-49

[70] C.f. Stansfield, A J. Holland, A J. & Clare, I C H. (2007) 'The Sterilisation of People with Intellectual Disabilities in England and Wales during the period 1988 to 1999' *Journal of Intellectual Disability Research* 51(8): 569-579

[71] C.f. Savell, K. (2004) 'Sex and the Sacred: Sterilization and bodily integrity in English and Canadian law' McGill Law Journal 49(4):1093-1141

[72] Shakespeare, T. (2008) 'Not Convenience, But Dignity: the stature of disabled people' *Clinical Ethics* **3**(1): 2-3

[73] Daily Mail, (2007) *Why I Want Surgeons to Remove My Disabled Girl's Womb*, Monday, October 8 2007: 5
The Daily Telegraph (2007) *Daughter Who Must Never Grow Up*
Daily Mail (2007) *Truly Humbling*, Friday, October 12, 2007: 30-31

At the time of the Ashley X case a spokesperson for the British Medical Association (BMA) said that: '*if a similar case occurred in the UK, we believe it would go to court and whatever decision was ruled would be in the best interests of the child*'.[74] We were told by people working in the field that these types of cases came to the Family Courts but very few people knew about their existence. These cases only usually come to the courts if there is a disagreement between parent and clinician or because the hospital wanted legal clarification before taking any action. What does this then mean for disabled young people and adults? Forced sterilization means that disabled people's fertility is compromised. Moreover, invasive medical intervention disrupts disabled people's bodily integrity and as such endangers their self determination.

An analysis of the arguments supporting the actions of Ashley X's parents and other parents in the UK provide an interesting insight into culturally disablist attitudes. The individuals supporting the parents' decisions all centre on either the dependency of the disabled child or the lack of support for families with a disabled child. These are, however, societal not physiological problems. As such, social policy should not aim to render disabled people's bodies more convenient for an ineffective support system, but rather strive to change the system. This would negate both the perceived need for intrusive, non-essential medical treatment and the argument for it. As Tom Shakespeare eloquently writes:

> '*If it is permissible to alter surgically disabled people for the convenience of their caregivers, this suggests that disabled bodies are objects without value and beauty and not worthy of respect… No clear evidence appears to have been provided in either case to prove that growing to adult stature or having normal female body shape or menstruation will be harmful or distressing to the individual, as opposed to inconvenient or confusing to her caregivers.*'[75]

In contrast, people opposing the treatment focused on the fact that fertility and menstruation had been selected but other non-essential medical treatment had not been deemed as appropriate.

Which ever side of the argument people fall, the reality is that disabled young people are still routinely having their right to retain their fertility denied. As such, many disabled people are unnecessarily infantilised and do not receive the equal status accorded to non-disabled people in becoming an adult. It is the dignity of these young adults which becomes compromised. It disappears off of the radar, with no accountability, no transparency of process and no mechanisms by which the voice or representation of the disabled people can be heard.

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[74] The Telegraph Online (2007) 'A Genuine Moral Dilemma, Say doctors': http://www.telegraph.co.uk/news/worldnews/1538647/A-genuine-moral-dilemma%2C-say-doctors.html

[75] Shakespeare, T. (2008) *op. cit.*

As Tom Shakespeare argues:

> '*A person who is child-sized and asexual is more likely to be treated as a vulnerable innocent: a passive human being to be protected and petted, rather than as a person possessing human rights and dignity, despite her obvious limitations. Dignity is not simply a matter of subjectivity or personal autonomy. It does not depend on being able to express autonomous choices or intervene in the world or interact with others. Dignity is a matter of the status, which is accorded to people, even those who are unable to express their views.*' [76]

Whilst these are extreme examples of the compromised nature of disabled people's fertility, this sentiment underpins many disabled people's experiences of wanting to have children. Many disabled people are denied their right to have children because of societal assumptions about their capacity or the charming view that they only want children so they've got someone to look after them. Lack of preparation for parenthood among disabled young people[77] and persistent negative attitudes towards disabled people becoming parents[78] decrease the likelihood that disabled people will want, or feel able, to construct a family. With this, and the financial restrictions and lack of accessible space,[79] family life is difficult or impossible to create and maintain. There have been some positive accounts of being a disabled parent;[80] however a systemic lack of support for disabled parents means that opportunities for family life are restricted.[81] In some cases this can lead to their children being taken into care and the family unit being changed, as the following example illustrates:

> **Case Study 4**
> *Mr Webster gave oral evidence to the Joint Committee on Human Rights during their inquiry into people with learning difficulties.*
>
> '*Many parents have told us about the injustice and heartbreak they have suffered. They have had their children taken away by Social Services in unjust practices. They told me that when they asked for support, they did not get any until it was too late... I talked to parents with learning disabilities about Child Protection. They have*

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[76] ibid

[77] Olsen, R. & Clarke, H. (2003) *Parenting and Disability: Disabled parents' experiences of raising children*, Bristol: Policy Press

[78] C.f. Booth, T. (2000) 'Parents With Learning Difficulties, Child Protect and the Courts' *Representing Children* 13(3): 175-188
Campion, M J. (1995) *Who's Fit to Be a Parent?*, London: Routledge

[79] Gordon, D. et al. (2000) *Poverty and Social Exclusion in Britain*. York: Joseph Rowntree Foundation.

[80] C.f. Wates, M. & Jade, R. (1999) *Bigger Than the Sky: Disabled women on parenting*, London: Women's Press

[81] Goodinge, S. (2000) *A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role*:
http://www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsInspectionReports/DH_4005103?IdcService=GET_FILE&dID=22754&Rendition=Web

*no respect for parents with learning disabilities. Too often they do
not listen and understand their learning disability. A lot of parents
with learning disabilities do not know about their rights. They are
told things that happen. A mum with a learning disability went to
hospital to have a baby, but Child Protection was there, waiting to
take the baby away, and she never got to bond with her son. This
is a human rights issue. Sometimes, when parents with learning
disabilities have two or three children, they have to pick which
child to keep because Child Protection think they cannot cope.
One lady told me that in the end she lost all her kids...*[82]*

It is not surprising that, of the disabled people we asked in our 2008 survey,
62% of respondents felt that they would not be able to have children
(including through adoption or fostering) if they wanted to.

This section has looked beyond choice and control to discuss how disabled
people's lives are affected by disablism in their interactions with their local
communities and other people. The restrictions that frame disabled people's
choice and control extend to people's self determination of their own bodies,
the realisation of their sexuality and their ability to create and sustain family
life. Judith Butler, in her exploration of modern constructions of gender,
describes sexuality as '*an improvisational possibility within a field of
constraints.*'[83] Yet disablist barriers do not allow for this improvisation,
spontaneity and independence that the exploration of sexuality demands.

For many disabled people sexual exploration and family life become a
planned activity, sometimes needing the facilitation of others to achieve the
desired outcome. When disabled people cannot negotiate and navigate these
interactions with others, their sexuality and family life becomes constrained.
Worryingly for many disabled people, the fundamental human right to self-
determination becomes dependent on the attitudes and whims of family
members, service providers and local commissioners.

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[82] Joint Committee on Human Rights (2008) *A Life Like Any Other? Human rights of adults
with Learning Disabilities (Seventh Report of Session 2007–08, Volume II):*
http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40ii.pdf
[83] Butler, J. (2004) *Undoing Gender*, London: Routledge

Section Three – Navigating Private and Public Spheres

This report has thus far focused on how disabled people's choice and control operates within confined conditions. This means that whilst disabled people can exercise choice and control they only have a restricted range of options of what they can do. In the previous section we explored this in more depth, focusing on the barriers that disabled people face in participating in their local communities, building friendships, having sexual relationships and creating a family life. This final section develops this theme further by looking at how the public sphere impacts on disabled people's ability to exercise choice and control in their private lives.

Moving Towards Personalisation

Over the past twelve years there has been a steady shift towards personalising public services, particularly the services that disabled people receive. A discussion paper written by the Cabinet Office's Strategy Unit states that an implication of pursuing the personalisation of public services is the need to '*support and encourage people to collaborate with services to meet their own needs.*'[84] Most notably this has occurred in the way that financial control over social care support is being gradually devolved to the individual. The introduction of direct payments has aimed to give disabled people more choice and control over which services they use and who provides them, helping to increase their ability to live more independent lives.[85] Unlike traditional care packages, direct payments devolve responsibility to disabled people to either commission their own services or employ their own staff directly.[86] As such, the disabled person, rather than the local authority, takes on employer responsibilities; including negotiating contracts and meeting health and safety and minimum wage requirements.

Similarly, individual budgets combine monies from a range of different funding streams including the Disabled Facilities Grant [87], Independent Living Funds [88] and Access to Work.[89] The evaluation report [90] of the individual budget pilots found that working age disabled people were more likely to feel like they

[84] Cabinet Office (2008) *Realising Britain's Potential: Future strategic challenges for Britain*: http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/strategic_challenges.pdf
[85] For further details see: DH (2008) *A Guide to Receiving Direct Payments From Your Local Council: A route to independent living*: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083561?IdcService=GET_FILE&dID=161919&Rendition=Web
[86] McCullen, K. (2002) *The Direct Approach: Disabled people's experience of direct payments Summary of findings and key recommendations*: http://www.scope.org.uk/downloads/action/publications/ExecSummaryrev_directpayments.pdf
[87] http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_4000642
[88] http://www.ilf.org.uk/
[89] http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347
[90] Glendinning, C. et al (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*: http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf

had choice and control in their lives when using individual budgets as opposed to traditional social care provision.

Following the Department of Health's green paper and white paper, [91] the Government concordat in the *Putting People First* initiative [92] outlines their commitment to independent living for disabled people and introduces the idea of personal budgets. The budget can be used in the same way as a direct payment or the individual can choose the service, with the commissioning responsibility being left with the local authority. Alternatively disabled people can use a mixture of both, as their needs or preferences dictate. Evaluations of personal budgets for people with learning difficulties found that over three-quarters of participants felt they had a better quality of life than before they had a personal budget. This resulted in 72% of respondents reporting that they felt that they were in more control of their lives after receiving personal budgets.[93]

Given this concerted effort by Government to devolve more funding, choice and control to the individual, the take up of these initiatives has remained relatively low. As of March 31st 2008, 55,900 adults in England [94] were receiving a direct payment, up from 40,600 adults the previous year. [95] A report from the Commission for Social Care Inspection [96] found in 2004 a number of barriers to disabled people using direct payments effectively.

Similarly in a survey of 600 social workers in adult services, only 17% of respondents felt well-informed about the concept of personal budgets and approximately 20% in regards to individual budgets.[97]

The devolution of budgets does offer disabled people an opportunity to have choice and control over the services they receive but the reality on the ground is concerning. Our survey of disabled people in 2008 found that only 37% had the skills they needed for day to day living. Even more worryingly 55% of disabled people told us that they did not often or never had opportunities to try new things and learn new skills, compared to just 19% of non-disabled people.

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[91] HM Government / DH (2006) *Our health, Our care, Our say: A new direction for community services*: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4127453?IdcService=GET_FILE&dID=456&Rendition=Web
[92] HM Government (2008) *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndguidance/DH_081118?IdcService=GET_FILE&dID=156660&Rendition=Web
[93] DWP (2008) R*aising Expectations & Increasing Support: Reforming welfare for the future*: http://www.dwp.gov.uk/welfarereform/raisingexpectations/fullversion.pdf
[94] CSCI / ONS (2008) *Social Services Performance Assessment Framework Indicators Adults 2007-08*: http://www.csci.org.uk/professional/PDF/PAF_2008_LO_02.pdf
[95] CSCI (2008) *The State of Social Care in England 2006-07*: http://www.csci.org.uk/PDF/20080128_SOSC_Summary_2007.pdf
[96] CSCI (2004) *Direct Payments: What are the barriers?*: http://www.csci.org.uk/PDF/direct_payments.pdf
[97] http://www.communitycare.co.uk/Articles/2008/10/22/109755/social-workers-lack-knowledge-of-personalisation-survey-finds.html

What this means is that whilst the Government is keen to roll out the personalisation agenda, many disabled people currently do not have the life skills they need to make use of these opportunities. They also lack the opportunity to develop these key life skills. Without these skills disabled people are disempowered. This results in just under a third of our respondents reporting that they did not get enough help and support to do most things when they wanted to.

Blurring Boundaries

An interesting consequence of this devolution of choice and control to disabled people is that it creates new relationships and dynamics in their everyday lives.[98] They are transformed into commissioners of services and employers of staff. This can be very empowering but it can also mean homes and private spaces become transformed into routined, administrative workplaces.[99] The distinction between personal and professional boundaries becomes a constant negotiation between the disabled person and their bespoke service circumstances. This occurs to differing extents dependent on what type of care package and funding the disabled person receives, however in every case everyday dynamics and practicalities change.

> *Case Study 1*
> *Riana is a young disabled person living independently in London. She is in receipt of direct payments.*
>
> *'It is so frustrating when you get new staff. You've got to start negotiating hours and routines from scratch. The direct payment really changes your relationship to care staff. You think you are in control because you directly employ the staff and do the paperwork, but they can easily change the balance of power by just ringing up and saying that they are ill. If they are off that morning it means I may not be able to get out of bed, which obviously affects my job.'*

Traditionally a distinction has been drawn between private lives and public activities; between the activities of a family in the home and an individual in the workplace. More recently, research has demonstrated that this distinction between private and public sphere is more blurred than first realised.[100] This blurring becomes even more acute when we consider the position of disabled people who employ and manage their own support. The introduction of employment law, contracts and procedures into home life fundamentally changes the lifestyle and dynamics of disabled people's lives. It requires them, to varying extents, to adhere to employment legislation and take on the

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[98] Stainton, T. & Boyce, S. (2004) ''I Have Got my Life Back': Users' experience of direct payments' *Disability & Society* 19(5): 443 - 454

[99] C.f. Llewellyn, S. & Walker, S. (2000) 'Household Accounting as an Interface Activity: The home, the economy and gender' *Critical Perspectives on Accounting* 11: 447-478

[100] Weintraub, J. & Kumar, K. (1997) Public and Private in Thought and Practice: Perspectives on a grand dichotomy, London: University of Chicago Press

responsibility of managing a team of staff. On the other hand, many disabled people hire people the same age as themselves with similar interests and build friendships with their staff. In either scenario disabled people are forced to think about how others view them in situations where this is not usually demanded. When undertaking personal phone calls or using the internet, many disabled people feel obliged to explain their activities to their support staff. This means that for disabled people they have little genuinely private space.

> ### Case Study 2
> Sanjay is a young disabled man, who employs a team of personal assistants through individual budgets and is living independently in London.
>
> 'It's a strange situation really. Sometimes I'll be on the phone with one of my friends and half way through I'll think, right my PA has only been hearing my side of the conversation. I spend the rest of the conversation watching what I am saying. Then for some reason when the phone call ends I feel like I have to explain what it was about to my PA, just in case they got the wrong impression. I know I don't need to, but it makes things easier I think.'

If your staff do not share your perspectives, for instance on sexuality, you may feel obliged to change the way you act around them. As such, the proximity of staff in one's home can place restrictions on freedom of expression. Despite the fact that the home is meant to be a private domain, once again for disabled people, public attitudes invade personal space. This blurring creates a simultaneous formalisation and personalisation of working relationships, both for the disabled person and the personal assistant.[101] As Marfisi [102] writes:

> 'The fact that we are acutely aware that the person who we are directing and from whom we are requesting services is in many cases being paid [at] minimum wage is another very powerful source of reticence and reluctance in our exercising assertive managerial skills... Many people are able to very effectively flow back and forth in the relationship from that of business to that of friendship and vice versa. This choice, however is a little more demanding of both parties having a clear understanding of expectations and how the relationship will manifest itself in different contexts.'

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[101] Glendinning, C. et al (2000) 'New Kinds of Care, New Kinds of Relationships: How purchasing services affects relationships in giving and receiving personal assistance' *Health & Social Care in the Community* 8(3): 201-211
Ungerson, C. (2005) 'Care, Work & Feeling' *The Sociological Review,* 53(2): 188- 203
Vasey, S. (1996) 'The Experience of Care' in G. Hales (Ed.) *Beyond Disability: towards an enabling society*, London: Sage
[102] Marfisi, C. (2002) 'Personally Speaking: A critical reflection of factors which blur the original vision of personal assistance services' *Disability Studies Quarterly* 22(1): 25-31

Furthermore, this new set of circumstances creates a power dynamic which disabled people have not traditionally experienced.[103] Jenny Morris[104] has argued that in paying for services directly, disabled people have a more equal relationship with care professionals, in that they need not feel grateful for the service as they have purchased it. She highlights that independent living is not the extent to which disabled people rely on care services to conduct day to day living but rather it is that they have the control to choose how these services are delivered to them.

The delivery of care services creates a further blurring between public and intimate activities. Intimate activities, such as going to the toilet or having a shower, become part of the workplace (the disabled person's house). For most non-disabled people these intimate spaces are not usually accessed by parents, friends or siblings. In contrast many disabled people allow non-disabled people, sometimes strangers, to access these spaces in order to fulfil their specified work. Julia Twigg,[105] in her exploration of the politics of bathing for disabled people, has suggested that bathing is seen culturally as an intimate activity and as such introducing another individual (possibly even a stranger) into this space creates embarrassment for disabled people. We could argue that introducing the employment relationship into these intimate spaces complicates these boundaries further.

> ### Case Study 3
> *Nathan is a 26 year old man, who lives independently, receives individual budgets and manages his own team of staff.*
>
> *'For me the situation becomes most difficult in intimate spaces. As a disabled person you are not sure what it is like for other people, because people tend not to talk about it. So when I'm taking a shower, I just want to be lost in my own thoughts, but you feel like you need to talk to the person in front of you otherwise you're being rude. Some personal assistants do find it difficult, so they try to have as little conversation with you as possible, and others just chat away trying to distract themselves. Sometimes you just want to stay in the shower for just that extra minute to finish the song you've been singing in your head or something. But you are consciously aware that someone is standing there above you, holding the shower and their arm is probably aching and they are getting hot from the steam. So you feel obliged to tell them you're finished.'*

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[103] Ungerson, C. (1997) 'Give Them the Money: is cash a route to empowerment?' *Social Policy and Administration*, 31(1): 45-53
Ungerson, C. (1999) 'Personal Assistants & Disabled People: An examination of a hybrid form of care and work' *Work, Employment and Society,* 13(4): 583-600
[104] Morris, J. (2004) 'Independent Living & Community Care: A disempowering framework' *Disability & Society* 19(5): 427-442
[105] Twigg, J. (1997) 'Bathing and the Politics of Care' *Social Policy and Administration* 31(1): 61-72
Twigg, J. (2000) *Bathing: The body and community care*. London: Routledge

Over the past decade there has been a burgeoning of literature illustrating how disabled people's lives disproportionately come under surveillance by professionals and Government officials.[106] However the majority of this literature around surveillance actually relates to medicalisation or the management of health. Elements of personalisation create a further layer of surveillance in disabled people's lives. As employers, disabled people need to administrate both the activities of their lives and their staff's work. This can include arranging staff tax forms, national insurance contributions and managing expenses. On top of this disabled people who use Access to Work[107] have to evidence and reclaim their expenditure. In order to receive this form of funding disabled people keep their receipts and record their activities. As such their lives become written, literally on the receipts they collect. All of these administrative activities mean that disabled people's lives become transparent and can be surveyed by officials.

> '*Everyone is so worried about ID cards, but our movements are totally traceable. The Government knows everything about our daily lives, from what changes I'm making to my bathroom to what I am doing at work.*'

It is therefore ironic to reflect that in achieving greater freedom in and control over their private activities, disabled people become closer to the official surveillance of the public sphere. A consequence of the blurred boundary of private and public for disabled people is that concerns about administration and employer roles enter everyday private thought.

> '*I find myself sometimes thinking about things like my staff's annual leave or something when I am just relaxing. You can't really get away from it because the staff and management are part of your everyday life.*'

This surveillance is part of a systematic reification of the restricted situation that disabled people experience. In order to fully live independently in many cases disabled people have to surrender their own right to a private life.[108] However it is pertinent here to note, that whilst the introduction of personalisation undoubtedly brings up the issue of the invasion of personal and private space, for those who need support this has always been the case. The key difference is that previously people would have had their needs met in an institution or by someone delivering domiciliary care services that were

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[106] C.f. Watson, N. et al (1999) *Life as a Disabled Child: A qualitative study of young people's experiences and perspectives* Edinburgh / Leeds: University of Edinburgh / Leeds
Paterson, K. & Hughes, B. (1999) 'Disability Studies & Phenomenology: the carnal politics of everyday life' *Disability & Society* 14(5): 597-610
Tremain, S. (2005) *Foucault and the Government of Disability*, Michigan: University of Michigan Press
[107] http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347
[108] Article 22 of UN (2008) *The United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD): http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

designed to meet the needs of the provider rather than the disabled person. The rationale behind personalisation to the disabled person is that finally they can be in control of how their lives are run and choose what services they receive.

Personalisation does create an interesting new temporal situation for disabled people – on one hand the choice and control of movement that personalised budgets offer and on the other a restriction on flexible time. There has been focus of the lack of spontaneity in the lives of families with disabled children,[109] however little research has focused specifically on the temporal restrictions on the lives of disabled adults. As we previously noted, our survey of disabled adults found that only 43% of disabled respondents could do things spontaneously in their day to day lives. This lack of spontaneity forces disabled people to choose between a spontaneous act and their care regime.

> *Case Study 4*
> *James is a 24 year old man living independently in London and is in receipt of direct payments.*
>
> *'As a disabled person, I rely on agency care funded by my direct payments so I can't really afford to be spontaneous. Everything has to be planned in advance, otherwise I go without. Like the other evening I randomly got asked whether I wanted to go to a concert as one of my friends had a spare ticket. I was really keen and did end up going, but this meant that I could not have a shower or eat for 12 hours or more. Bizarrely my care provision is designed to give me the freedom to enjoy my life when in actual fact it sometimes stifles my opportunities.'*

In this sense, with new flexibility, comes greater structure. Whilst many disabled people may seek to have more spontaneity in the services they receive, many are forced to keep to a pre-defined daily routine. Individuals can arrange for staff to support them in different settings and at different times, however making a spontaneous decision to change plans is still very difficult. Time for disabled people is experienced in a more linear fashion than for their non-disabled peers. This results in a lower level of freedom, choice and control.

It is a restricted context in which disabled people have to continually negotiate their role as employers and consumers of a service, but also as individuals living their everyday lives. This section aims not to necessarily critique the pursuit of the personalisation agenda in disabled people's independent living, rather it highlights the new tensions that arise from the employer-staff relationship. When considering this issue it is important to keep in mind that personalisation has not been extended to all areas of disabled people's lives (i.e. health services). As such there are many situations in which disabled people's personalised choice and control become negated; by health-related

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[109] Hallum, A. (1995) 'Disability and the Transition to Adulthood: Issues for the disabled child, the family, and the paediatrician' *Current Problems in Paediatrics* 25(1): 12-50

appointments for example. What this section does illustrate is that some disabled people are now positioned in a different relationship to choice and control. This creates new challenges and opportunities for them, however as Marfisi[110] suggests this needs to be viewed in a positive light:

'*If we are not claiming and embracing the personal pleasure and satisfaction of these movements we are doing a disservice not only to our history and to ourselves, but we are also sending an ambivalent message to society that [personal assistants] and [independent living] is all about struggle and effort and not that much about emancipation and enjoyment.*'

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[110] Marfisi, C. (2002) 'Personally Speaking: A critical reflection of factors which blur the original vision of personal assistance services' *Disability Studies Quarterly* 22(1): 25-31

Conclusions – Towards Equality for Disabled People

At the start of this report we highlighted that in 2005 the Government set the ambitious target that '*by 2025 disabled people should have the same opportunities and choices as non-disabled people and be respected and included as equal members of society*'.[111] We are now approximately a fifth of the way through the time allocated to meet this target. Despite this there is no robust baseline data by which to judge disabled people's progress towards equality.[112] Our report does, however, offer an opportunity in the interim to reflect on the situation of disabled people in 2008 and what issues will need to be addressed in the near future to achieve this ambitious target. If equality is based on the ability to exert choice and control over your life, to be able to act spontaneously, to make friends, have relationships and receive services that meet individual needs, then our research has illustrated that disabled people's ability to act as equal citizens remains unachieved.

This report has explored some of the key barriers which underpin disabled people's ability to become equal citizens in British society. Our findings have demonstrated that there is a disjuncture between disabled people's perception of how much choice and control they have over their daily lives and the practical realisation of that choice and control. In reality they only have restricted opportunities to realise choice and control in their lives. When they do exercise choice and control, they are only doing so within a restrictive context which means that they do not have equal choice and control to participate in their community, make friends and pursue opportunities to have fun. This extends to disabled people's self determination of their own bodies, the realisation of their sexuality and their ability to create and sustain family life. The disablist society in which we live deprives disabled people of their ability to act spontaneously, have self-determination of their lives and mobilise the freedoms of choice and control.

Our report has explored the way that disablism is enacted in disabled people's private lives. The employment of staff and the transformation of the home into workplace have created new blurred spaces in which disabled people and their staff have to actively negotiate the boundaries between, public, private and intimate lives. With it, the personalisation agenda and the relative freedom, choice and control it brings has brought greater surveillance of disabled people's private lives. We have seen how many lives become written, literally on the receipts they collect. All of these administrative activities mean that disabled people's lives become transparent and can be surveyed by officials. This surveillance is part of a systematic reification of the restricted situation that disabled people experience.

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[111] PMSU (2005) *Improving the Life Chances of Disabled People*: http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf
[112] The ratification of Article 31 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) will provide an opportunity to collect data to inform the monitoring of progress on disabled people's human rights.

(Dis)abled Citizens?

Finkelstein[113] once described disabled citizenships in a disablist society as being: '*unable to function socially as an independent citizen having the same rights and expectations as 'normal' people*'. This attitudinal barrier has positioned services for disabled people as being geared towards meeting functional needs rather than the pursuit of life chances. First and foremost support services are about citizenship. For example social care services are not ends in themselves – getting out of bed does meet a functional need, however it does not make a life worth living. It is the things you do once you are out of bed that count.

For some disabled people, lack of appropriate support to get out of bed, cook meals or go to the toilet means that they cannot enjoy full and equal citizenship. We need to understand better what citizenship means for disabled people in order to design services that can support its realisation. The recent focus in *Putting People First* on choice, control, independence and personalisation[114] is very welcome but these concepts do not go far enough in describing the things we think people ought to be able to achieve. What we mean by this is that national policy and service delivery still does not understand the core outcomes that all disabled people need to achieve in order to become equal citizens.

Jenny Morris[115] draws on principles written by the then British Council of Disabled People[116] which underpin equal citizenship. These principles are:

- that all human life is of value
- that anyone, whatever their impairment, is capable of exerting choices
- that people who are disabled by society's reaction to physical, intellectual and sensory impairments and to emotional distress have the right to assert control over their lives
- that disabled people have the right to participate fully in society

Our research has, however, demonstrated that disabled people face significant barriers in realising these principles of equal citizenship. Jenny Morris[117] has written elsewhere that these barriers are determined by debates surrounding the responsibilities of citizenship. She states that debates around disabled citizens' responsibilities tend to be limited to opportunities to move from receiving benefits to be in some form of paid employment. When other aspects of disabled people's citizenship are debated they characterise disabled people as being passive of other people's citizenship responsibilities.

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[113] Finkelstein, V. (1991) 'Disability: An administrative challenge?: The health and welfare heritage' in Oliver, M. *Social Work: Disabled people and disabling environments*, London: Jessica Kingsley

[114] Through Direct Payment, Individual Budgets and Personal Budgets

[115] Morris, J. (1993) *Independent Lives?: Community care and disabled people*, Basingstoke: Macmillan

[116] now named the United Kingdom's Disabled People's Council (UKDPC)

[117] Morris, J. (2005) *Citizenship and Disabled People: A scoping paper prepared for the Disability Rights Commission*: http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship%20and%20disabled%20people.pdf

Towards Equal Citizenship

What this suggests is that we need to rethink the way we conceptualise both disabled and non-disabled people's citizenship. One way of achieving this could be to develop an outcomes framework for adults, which helps to focus attention from all public service providers on what services are there to achieve; namely the equal citizenship irrespective of need. An outcomes approach which draws on human rights principles is a prerequisite for equality of citizenships because it allows us to set a benchmark that applies to all adults, not just those who are in need of support services. In setting out clear goals for all citizens, regardless of need, it becomes possible to design and align services that all work towards this common goal. Only then will disabled people receive personalised services which enable them to achieve the outcomes that the state is supporting all adults to realise.

The Equality & Human Rights Commission (EHRC) has proposed a similar model in their recommendations around reform for the social care and support system.[118] The proposed outcomes model draws on evidence from the Equalities Review[119] and is based on the human rights principles of the Human Rights Act,[120] the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[121] and the Disability Discrimination Act.[122] The report writes that the challenge for the care and support system is that historically it has been predicated on a definition of individual functional need rather than a conception of rights and duties which enable people to become equal citizens. In this paper the EHRC suggests that this system reform could be met through the introduction of a '*national rights-focused framework of outcomes*' for all disabled and older citizens. A national framework of guaranteed outcomes, based upon the principles of human rights, could offer a clearer route for disabled people to be treated as equal citizens. Furthermore it would offer an opportunity to receive personalised services which focus on these rights-based outcomes.

A rights-based outcomes approach allows us to look beyond individual services and consider how all public services interact to support or deny equal citizenship to citizens (disabled people). To live a fulfilling and active life a disabled person may need social care services, health services, employment services, transport and housing services but at the moment none of these services are designed with a view to achieving this. They are coordinated in

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[118] EHRC (2009) *From Safety Net to Springboard: A new approach to care and support for all based on equality and human rights*:
http://www.equalityhumanrights.com/en/publicationsandresources/Documents/Equalities/Safetynet_Springboard.pdf
[119] Cabinet Office (2007) Fairness and Freedom: The Final Report of the Equalities Review:
http://archive.cabinetoffice.gov.uk/equalitiesreview/upload/assets/www.theequalitiesreview.org.uk/equality_review.pdf
[120] Human Rights Act [1998] C. 42:
http://www.opsi.gov.uk/ACTS/acts1998/ukpga_19980042_en_1
[121] UN Convention on the Rights of Persons with Disabilities (UNCRPD):
http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf
[122] *Disability Discrimination Act* [1995] C.50:
http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_1

isolation, in the main focusing on functional outcomes and minimum standards. An outcomes framework, underpinned by human rights principles, would help to make it clear that public services have a purpose and to help join-up these services (regardless of funding stream or Government department) to support true expression of citizenship.

To return to our discussion of the relationship between disabled people's public and private lives, it is important to consider what impact an equal conception of citizenship would have on the way in which we think about services delivery. As we noted in Section Three, Government policies tend to steer clear of the private lives of its citizens, but for many disabled people public services are the enabling factor in the realisation of a private life. It could be argued that personalised budgets (including direct payments) in some way could be seen to absolve the state of their own responsibilities to the citizen by placing control and therefore responsibility of outcome in the hands of the user. Whilst this is in many ways desirable to guard against the state retaining too much control of its citizens, at the other end of the spectrum it could be seen as the state washing its hands of people and leaving them to try to attain equal outcomes without support. This leads us to conclude that perhaps in devising a rights-based outcomes framework for all adult citizens, one of these core outcomes should relate to private and family life and give full recognition of the importance of relationships, fun and friendship.

Our report has demonstrated that independence, choice and control are meaningless when they operate in restricted circumstances. Without services and support for disabled people being focused towards equal citizenship, the life chances of disabled people will be restricted and their experiences will continue to be characterised by marginalisation and disablism. Jenny Morris[123] has written that disabled people's unequal citizenships mean that they will '*not achieve [equal] social rights without fulfilling the responsibilities of citizenship. Yet for disabled people, social rights are necessary in order to fulfil these responsibilities'*. In light of this we have argued that society and the Government need to rethink their approach to delivering services for disabled people. Whilst specialist services that are based on equal citizenship need to be developed, there is a wider need for mainstream services (including childcare, community policing and employment) to be motivated towards meeting rights-based outcomes for all adults irrespective of need or circumstance.

In exploring and exposing further the restricted spaces in which disabled people operate their independence, choice and control we have raised the question of how the Government, the Third Sector and disabled people themselves can work together to challenge this constrained position of disabled people as unequal citizens.

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[123] Morris, J. (2005) *Citizenship and Disabled People: A scoping paper prepared for the Disability Rights Commission*: http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship%20and%20disabled%20people.pdf

If disabled people are going to achieve equal citizenship by 2025, as the Government's ambitious target aims towards, what steps need to be taken?

We have explored how this relates to the way we think about services and the way in which they are delivered. The authors of this report believe that this is the basis of an important debate which needs to be had over the next few years as we move to reform systems which affect disabled people's lives (i.e. welfare and social care reform). What is clear from this research is that if we do not undertake this project and challenge the disablist society in which we live, then disabled people will never achieve equal citizenship or have the freedom to have meaningful choice and control over their lives.

Methodology

In total four sets of data inform the content of this report.

The Scope Quiz 2008

Firstly, in April 2008 we launched the Scope Quiz 2008, focusing on the experiences of disabled people. The survey ran for 12 weeks and was promoted through Disability Now and established disability forums.

Surveys were available online (hosted by Snap Surveys), in print and in alternative formats. The survey was divided into two sections, the first focusing on disabled people's self perceptions (20 questions) designed to quantitatively understand disabled people's experiences of disablism in Britain. The second section was a series of nine demographic questions. The overall response rate for the survey was extremely high (1320 respondents), which is well above the average for this type of survey.

The sample consisted of approximately 47% males and 51% of females (two did not respond to this question). The number of respondents aged under 16 years was 1%, between 16 and 29 years were 10%, between 30 and 49 years 31%, between 50 and 64 years 39% and between 65 and 80 years 15%, over 80 years of age 4%. 93% of respondents were of a white ethnic background and only 7% had non-white heritages. 80% of respondents identified as heterosexual compared to 4% who identified as either a gay man or a lesbian and 3% bisexual. 3% reported that they did not know what their sexual preference was and 2% did not respond.

The distribution of respondents' impairments[124] was varied including:

- Physical/mobility   69%
- Long term medical condition   46%
- Hearing impairment/deaf   17%
- Cerebral palsy   15%
- Mental health condition   14%
- Visual impairment   12%
- Learning difficulty   12%
- Communication impairment   10%
- Autistic spectrum condition   2%
- Don't wish to disclose   2%

The employment status of respondents was equally diverse:
- Full time   13%
- Part time   8%
- Full time education   4%
- Part time education   4%
- Full time voluntary work   1%
- Part time voluntary work   13%

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[124] NB: Many respondents had more than one impairment, and therefore the total exceeds 100%.

- Seeking employment   3%
- Retired   36%
- Carer   3%
- Not in Education, Employment or Training   27%
- Did not respond   2%

The Tickbox Survey of Non-Disabled People

The second set of data was based on a survey we commissioned (run by Tickbox), which focused on ten questions of the Scope Quiz 2008. This second survey was for non-disabled people and was commissioned so that a comparison could be based between the self-perception of disabled and non-disabled people. This online survey received 1500 responses from non-disabled people.

Literature Review

The third set of data came from a comprehensive review of existing literature, which has been used to frame the analysis in this report. The literature reviewed was compiled through online journal databases and academic book searches. An online review of Third Sector and Government publications was also undertaken.

Focus Group and Qualitative Analysis

The final set of research data was collated in a small focus group of disabled people. Participants were asked about their experiences and opinions of managing personal assistance through direct payments, individual budgets or personal budgets. This data was used to inform the third section of this report. Data from the focus group was coded under relevant thematic headings. A code list was developed, with each code carefully defined to ensure consistency of coding. This enabled us to develop the narrative for our discussion in the final section of this report.

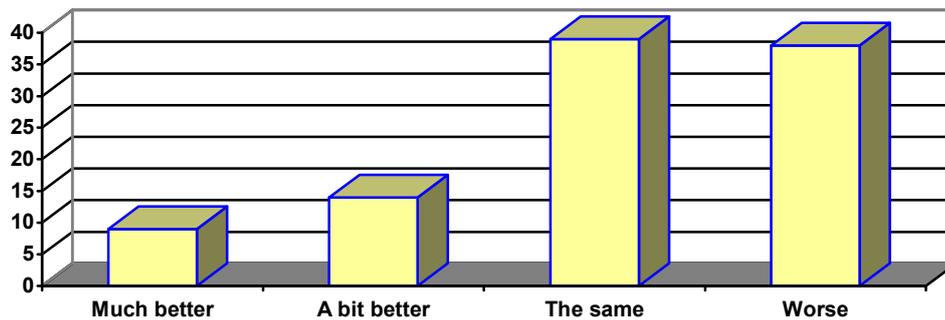## Appendix A – Disabled People's Responses

Perceptions of Control

How much choice and control do you have over what happens in your life?

a)	A lot of choice and control	42
b)	Some choice and control	41
c)	Little choice and control	14
d)	No choice and control	3
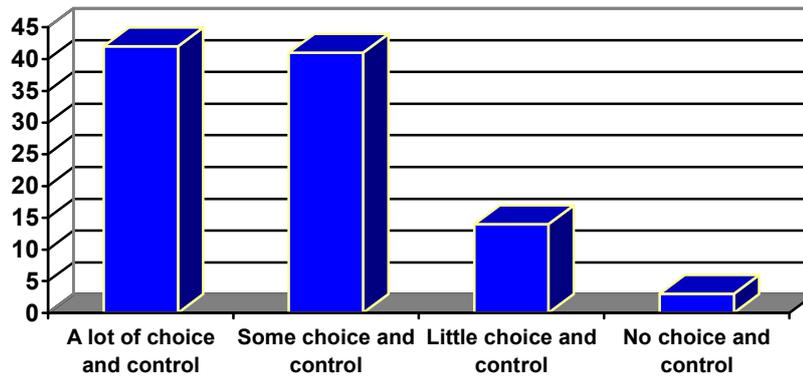
What do you think your quality of life will be like in five years?

a)	Much better	9
b)	A bit better	14
c)	The same	39
d)	Worse	38

How confident are you in dealing with day to day things?

a) Very confident   29
b) Fairly confident   46
c) Not very confident   18
d) Not confident at all   7
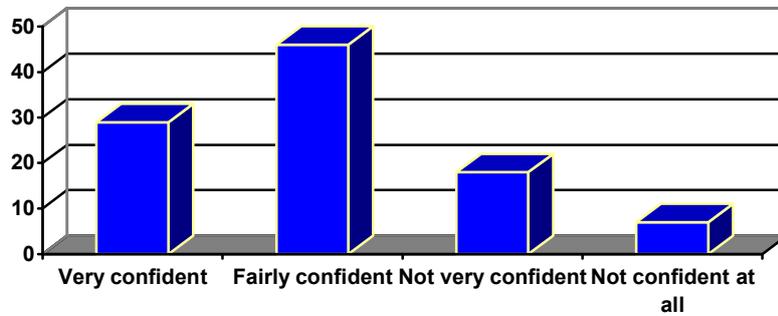
How easy is it for you to get your views and opinions listened to?

a) Very easy   19
b) Fairly easy   43
c) Fairly difficult   27
d) Very difficult   11
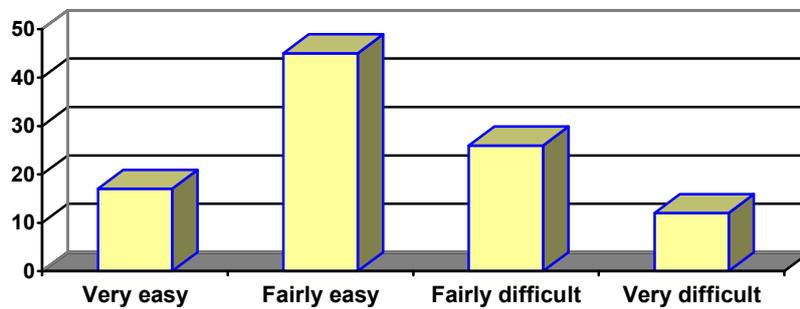
How easy is it to get the information you need to make informed choices?

a) Very easy   19
b) Fairly easy   43
c) Fairly difficult   27
d) Very difficult   11

41
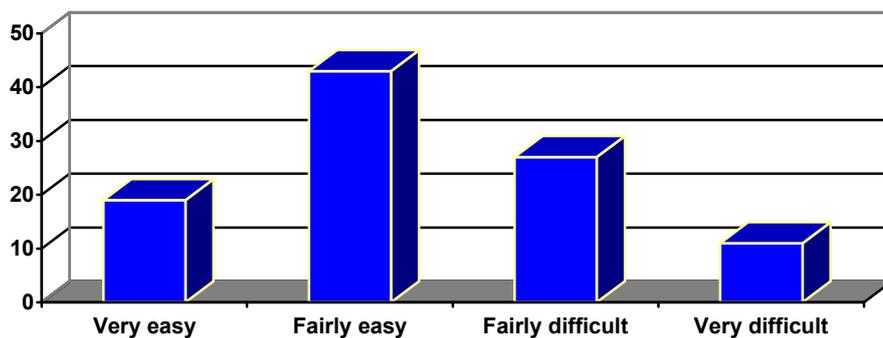
Relationships and Community Life

Community Life

Do you feel able to take part in community events, groups and leisure activities near you?

a) Yes   20
b) Quite often   20
c) Not very often   35
d) Rarely/never   25
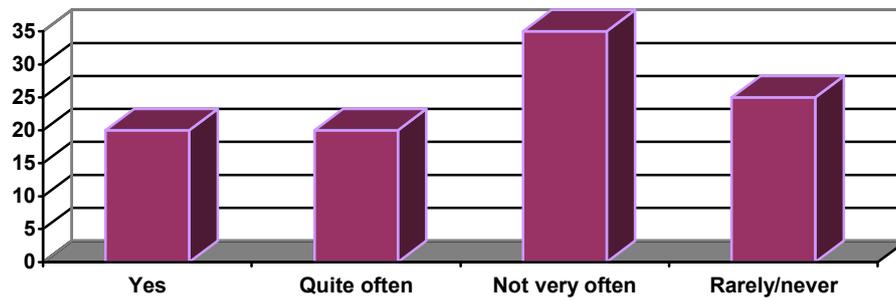
**Do you feel safe and secure at home and in your local community (during the day and at night)?**

a) Nearly always   51
b) Quite often   29
c) Not very often   14
d) Rarely/never   6
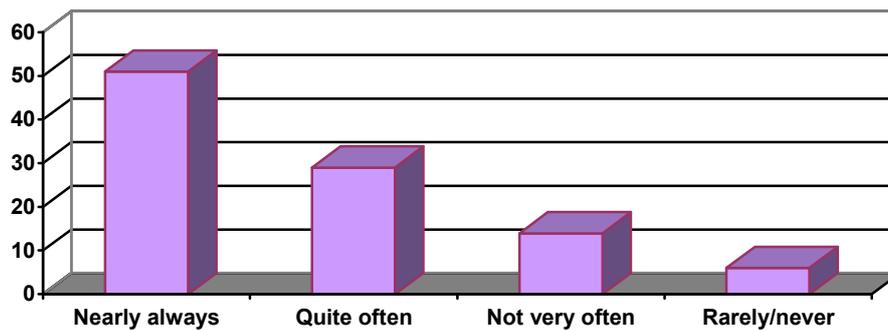
Building Friendships and Relationships

How regularly do you see people that you enjoy spending time with (e.g. friends or family members)?

a)   Very regularly   27
b)   Quite regularly   38
c)   Not very regularly   27
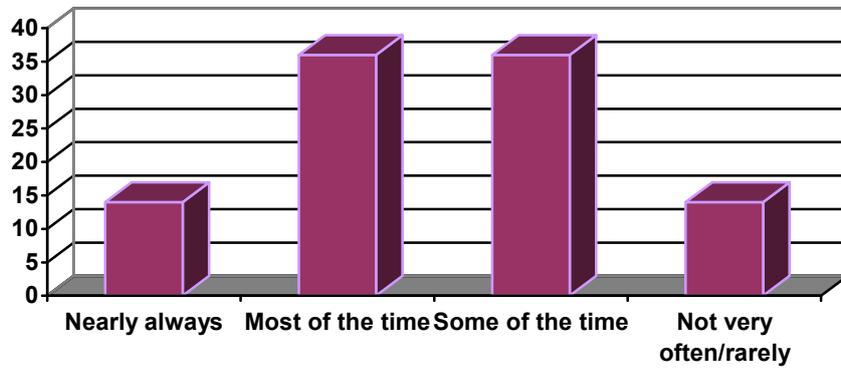d)   Rarely/never   8
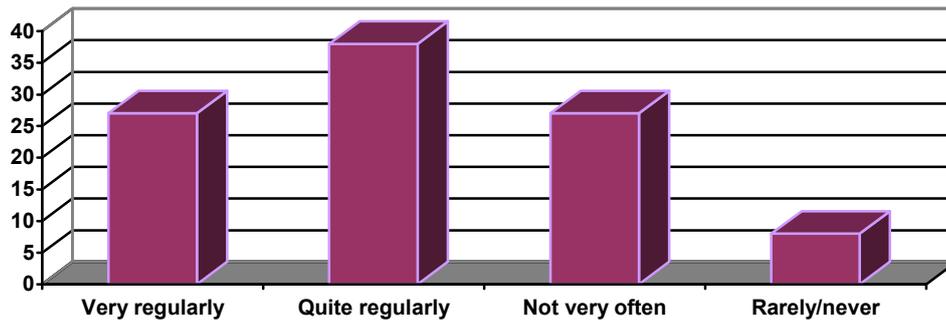
How much fun do you have in your everyday life?

a)   Lots of fun   13
b)   A fair bit   29
c)   Some fun   34
d)   Very little   24
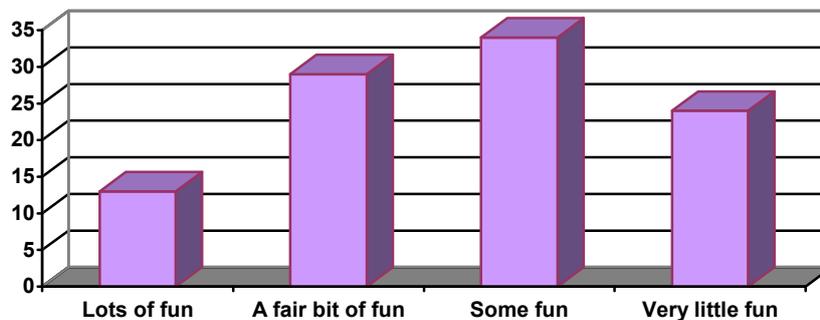
How often do you feel happy and content?
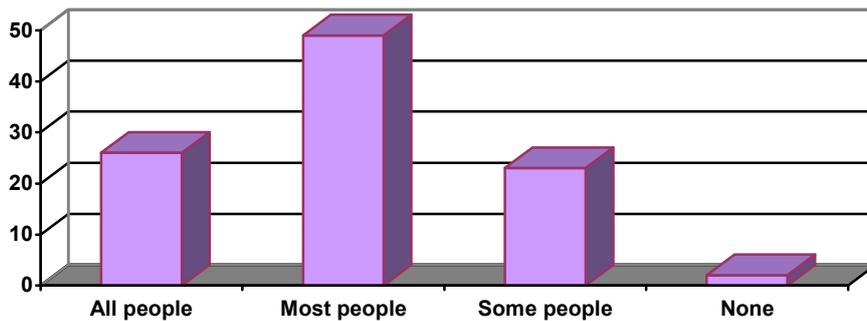
a) Nearly always   14
b) Most of the time   36
c) Some of the time   36
d) Not very often/never   14
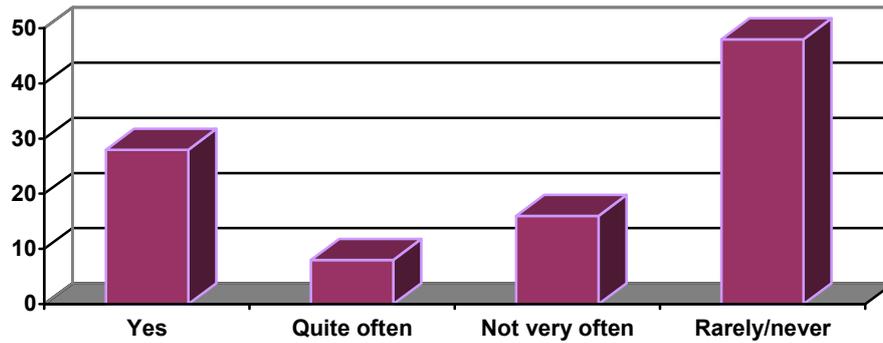

Having Children and Building Families

How many of the people you know do you think respect you and treat you well?

a) All of them   26
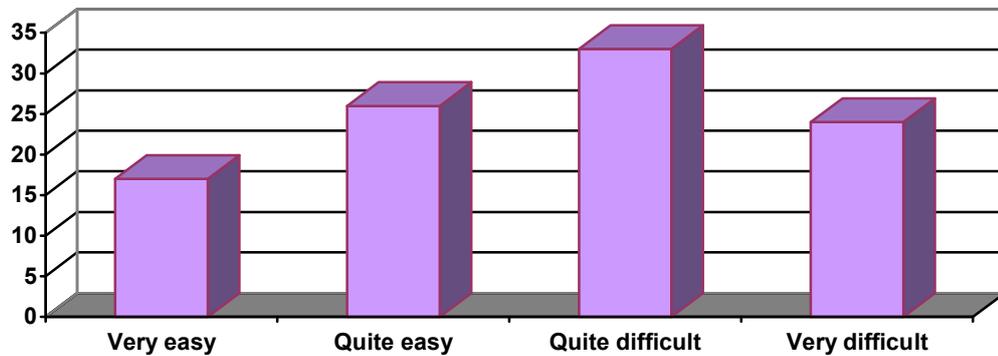b) Most of them   49
c) Some of them   23
d) None of them   2

Do you have the opportunity to explore your sexuality or have a sexual partner(s)?

a) Yes 28
b) Quite often 8
c) Not very often 16
d) Rarely/never 48

How easy is it for you to do things spontaneously (e.g. go out for a meal, invite friends round, go shopping)?

a) Very easy 17
b) Quite easy 26
c) Quite difficult 33
d) Very difficult 24

How likely is it that you could have children if you wanted them (including adopting or fostering)?

a) Very likely/I have children   28
b) If I meet the right person   10
c) Not likely   17
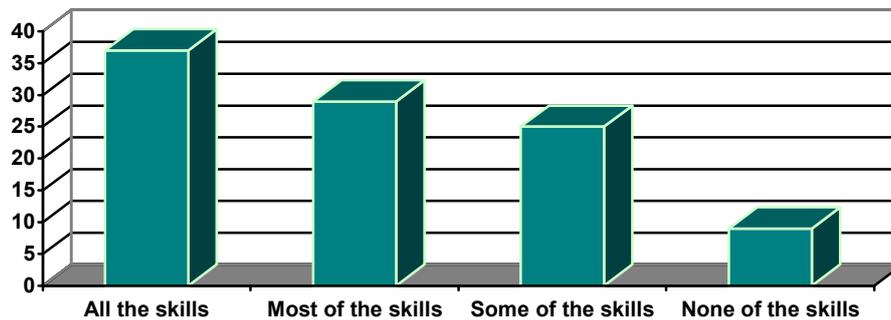d) Little or no chance   45
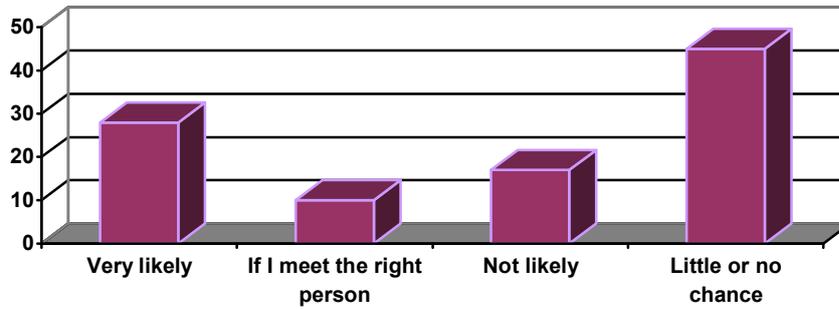
Private versus the Public Sphere

**Moving Towards Personalisation**

Do you have the skills you need for day to day living? (e.g. to manage money, to understand information, to know where to get help or advice)

a) All the skills — 37
b) Most of the skills — 29
c) Some of the skills — 25
d) None of the skills — 9

How often do you have opportunities to try new things and/or learn new skills?

a) All the time — 12
b) Quite often — 33
c) Not very often — 37
d) Rarely/never — 18
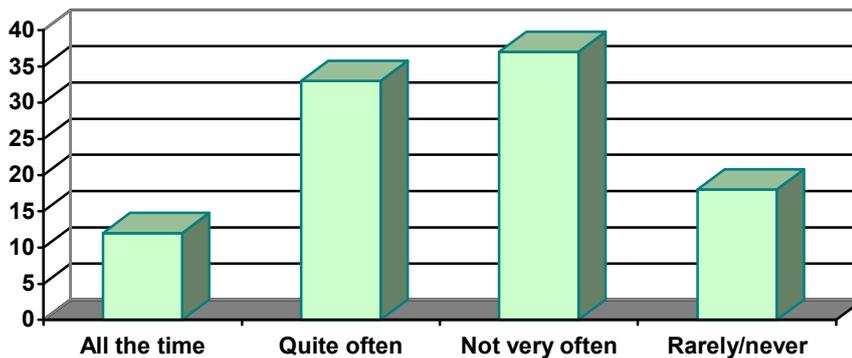
Unequal Citizenship: The personal is political!

Unequal Citizenship: The personal is political! is the first in a series of **Disablism Audits** by Scope.

Scope's **Disablism Audits** aim to provide a more robust understanding of disablism in modern Britain, through an exploration of disabled people's lives, experiences and ambitions.

Time to Get Equal supports local campaigning on issues which matter to disabled people.

For more information about disablism in Britain and Scope's other campaigning activities please **visit www.scope.org.uk** or **call 020 7619 7298** or **email ttge@scope.org.uk**

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You can support Scope's work in a number of ways by going to **www.scope.org.uk/support**

For information and advice on cerebral palsy, disability issues and Scope's services, visit **Scope Response** at **www.scope.org.uk** or call **0808 800 3333** or text SCOPE followed by your message to **80039**

FRSB
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For disabled people achieving equality.