



Life, not numbers

a report into the experiences of
disabled students in higher education
using personal care packages



national union of students

Foreword



Welcome to the NUS Disabled Students' Campaign report, *Life, not numbers*, about the experiences of disabled students in higher education who use personal assistants.

The NUS Disabled Students' Campaign believes all disabled students using personal care should be able to enjoy university life to its full potential. However, as our interviews with disabled students show, there are still many barriers to be overcome before this can become a reality. The NUS Disabled Students' Campaign believes everyone should have the right to pursue education to their full potential. The lack of 'portability' inherent in the current system of care packages prevents students from moving freely to achieve this potential and is therefore a breach of their basic human rights.

In the wake of this report the NUS will provide full support to disabled students as they devise a campaign. Disabled students need to be empowered to speak out about the barriers they face and funding bodies have a duty to involve them in decisions about their care.

The NUS Disabled Students' Campaign is determined to ensure that disabled students have a more positive experience in higher education. We are calling on students' unions, higher education institutions, local authorities, and government to respond to the report's recommendations.

Adam Hyland

National Disabled Students' Officer

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Kathleen Grehan

Liberation Research and Development Officer

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“Organising my care package is a constant worry and this affects my academic studies. The time I could spend reading and going to classes is impeded by having to keep badgering people. I am always on the phone or the computer to someone to sort out my support.”
(NUS case study interviewee, 2009)

Executive summary

Current government legislation and policy affecting disabled people who use personal care packages has been developed with the aim of reducing the inequality between disabled and non-disabled people. Despite this, research suggests that barriers to achieving better personal care packages¹ for disabled students still exist.

Current research about disabled students who require personal care while studying at university is mainly quantitative. In 2010, according to the Department for Culture, Media and Sports there are 10 million disabled people in the UK. In 2008/09 there were 86,000 disabled people receiving direct payments² in England with another 3,017 in Scotland³. In the same year, however, according to the Higher Education Statistics Agency (HESA) there were 95 disabled students attending university and receiving personal care support; this very low figure is unlikely to reflect

¹ Personal care packages are the services that local authorities provide to disabled people who need care. A care package can consist of both equipment and the provision of personal assistants or the funding to purchase their services. Personal assistants carry out a variety of tasks related to personal care needs such as domestic duties (cooking, cleaning or shopping), personal hygiene, transport or basic medical needs (i.e. injection)

² A disabled person’s personal budget can be paid directly, enabling the claimant to purchase the required services. People receiving direct payments take on the responsibility of employing people and dealing with tax and national insurance.

³ <http://www.communitycare.co.uk/Articles/2010/04/07/114232/Backing-for-Scots-plan-to-make-direct-payments-default.htm>

the true number of students with personal care needs (more details on page 16).

This research by the National Union of Students (NUS) adopts a qualitative approach in order to focus more personally on students' experiences of using personal care packages and to pinpoint the main barriers they faced while applying to and attending university. It also allows the students to talk about improvements that they think are required.

The report is in two parts. Part One outlines the background to the study, outlining current government policy and previous research. Part Two focuses on our interviews with thirteen disabled students⁴ in higher education who need personal care, looking at their experiences of using care packages while applying to or studying at university. Despite the fact that they came from a variety of backgrounds, they related similar experiences with the administration of their care packages.

The interviews were thematically analysed in the following areas:

Choice of university/course

Disabled students with personal care packages do not have the same access to universities and courses as other students. They encounter many barriers when researching their preferred university. The information provided by universities often looked encouraging but merely

⁴ There are no conclusive statistics on how many higher education students use personal care however, because of the qualitative nature of the research, 13 interviews allowed for in-depth case studies. From the interview responses it appeared that data saturation was reached and it was unlikely that more interviews would give fresh results (see Appendix A). The responses are discussed in the light of current quantitative research to ensure a balanced argument is presented

camouflaged a lack of both the political will and the resources needed to provide genuine access to students using personal assistants⁵.

Disabled students' number one priority in choosing universities is access and their choices are often dictated by the level of access provided rather than the courses offered. Students often avoid courses that involve placements abroad as they believed personal assistant support would be too difficult to coordinate. This lack of choice means that this group of disabled students' rights to equality in education under article 24 of the UN Convention on the Rights of Persons with Disabilities (CRDP)⁶ are not being upheld.

Starting at university

Starting at university and preparing for that start was one of the main themes discussed by students. During sixth-form college and further education care packages are generally satisfactory; however the same quality of support is seldom available at university. Students all consider that getting support right from the start is very important and that without it in place they could not access day-to-day life or be successful in their studies. Information, advice and guidance (IAG) about support and equipment is inadequate and often information given in one area does not apply in another.

Students attending university in their home area

All interviewees who attended university in their home local authority area identified two issues. First, there is a lack of information, advice and guidance (IAG) about who should be responsible for providing the care service. Secondly, social services and universities tend to argue about who should be responsible for funding certain types of support. All this

⁵ Personal assistants, who are employed either by the local authority or the disabled person directly, are responsible for undertaking the care component of the package of services.

⁶ Article 24: Education - requires that disabled people to be given full and equal rights to an education through the Human Rights Act 1998.

has an impact on aspirations and can cause people to doubt their decision to attend university.

Renegotiating care packages

Under Articles 18 and 19 of the United Nations Convention on the Rights of Persons with Disabilities students should have freedom of movement. If the obstacles involved in arranging care packages restrict this freedom then this is in direct contravention of their rights.

Students who move to a new area for their higher education hit additional difficulties in starting at university when they have to renegotiate their care packages.

These include:

- Students face inadequate levels of support because, mostly, new local authorities are seldom prepared to support them and often try first to deny responsibility and, secondly, only provide a very limited care package.
- Professionals often display negative attitudes to disabled students' decisions to study and/or move away from home.
- There is a lack of information, advice and guidance (IAG) and unclear law about where the responsibility lies for providing a care service.
- Assessment criteria, rates of pay and living expenses for personal assistants are inconsistent.

Students do not expect such obstacles and overcoming them is time-consuming and undermining.

Support provided by universities

Most participants in our study receive excellent support from their Disabled Students' Allowance (DSA)⁷ assessors. However, sometimes the support available under DSA is inappropriate for their care needs, leading to arguments between universities and social services as to who should take on responsibility for funding the support. Some universities fail to make reasonable adjustments to accommodation (their duty under the Disability Discrimination Act 1995).

Assessment procedures

Interviewees' experiences of being assessed for personal care are mixed, but mainly negative. Often the assessment is negative and intrusive. Several of our interviewees stated that as providers are always looking to offer no more than the bare minimum they – the students – feel they have to present a 'worst-case scenario' when describing their needs, as the assessment is made on numbers (how many times a day a person requires specific support rather than how much care is needed to ensure all needs are met). This sort of assessment does not always accurately reflect the amount of care required.

In addition, social workers do not always want to recognise that university life is more than just studying. Some students fear the annual review of assessments because social services attempt to cut budgets. Thus the assessment procedure often results in a care package being offered that is inadequate and does not reflect the true level of care required.

⁷ Higher education disabled students can claim extra funding – Disabled Students Allowance (DSA) – to ensure that they have equality of access to take part in university studies. This support is available to disabled students with a wide range of impairments, not all of whom will require personal care.

Some students cannot obtain funding to pay for their personal assistant's accommodation and to have their own accommodation adapted. Obtaining equipment is often difficult because it is unclear whether health authorities or social services are responsible for purchasing it.

Care agencies vs direct payments

A significant number of interviewees experience poor and unreliable services from personal assistants provided by agencies. They believe that some care agencies are too profit-orientated. Opting for direct payment schemes that allow them to employ their own personal assistants is empowering for some people, but bureaucracy involved in doing so can be a worry. The disabled students interviewed indicated a preference for direct payments but also felt that more support and advice about how to employ and manage their staff would be welcome.

Courage and capacity: fighting for adequate services

All the difficulties outlined can be challenged, if students have the energy and capacity to do so. Those who are assertive and challenge arbitrary decisions often obtain more funding or support. Others opt to rely on their families in order to avoid the daunting prospect of challenging decisions. Nevertheless everyone feels in the same situation of being compelled to appeal for help in order to obtain services that should be a matter of right.

Effect on students' university experience

The time-consuming business of arranging care packages and gaining accessible accommodation interferes with academic studies and creates barriers to social lives. Some students were unable to socialise with their non-disabled peers because rooms or buildings lacked access; one left her residential hall and returned to live at home. Students who are not

getting enough hours of personal care say that this harms their general well-being and mental health.

We found that disabled students who use personal assistants while at university had to overcome many barriers and still did not have the same access to the overall university experience as students who do not have personal care needs.

The choice and control exercised by non-disabled university students is not always available to disabled students who use personal care support. Although the personalisation agenda aims to improve the situation for all disabled people the current experiences of this group of students do not reflect of the equality of choice that should be available.

"If I want to go to the union in the evening then I cannot get the support. I am only entitled to care on specific hours during the week. I need to justify every one of these hours that I use and show they are based around my daily life. In total I have 40 hours a week in my care package, not including the hours I use at university" (An interviewee in Scotland, 2009)

Recommendations

Our recommendations aim to help disabled students have a more positive experience in higher education.

Disabled people have a right to be able to live independently in the way non-disabled people take for granted. There is now more awareness about disability and discrimination but to achieve equality for disabled students and give them full access to their rights drastic changes need to be made to policy and practice.

National advocacy service

Disabled students should be able to access a national advocacy service that would work alongside them and empower them to have the confidence to represent themselves.

The national advocacy services should make a standard set of information available to students.

NUS Disabled Students' Campaign should:

- work to see a national advocacy service established
- develop a partnership with a range of different advocacy organisations to look at their frameworks
- develop a research project in order to understand advocacy services

Disabled Students should lead the National Advocacy Service and the service should be run by appropriate organisations.

Clarity of information, advice and guidance

Information, advice and guidance (IAG) should to be improved and be individualised to meet the needs of students. Within any change of system students should be given more flexibility, choice and control.

There should be greater clarity over how funding can be obtained to cover care support needs.

Awareness campaign

Together with an improvement in information, advice and guidance (IAG), NUS should launch an awareness campaign so that disabled students can take control of the services they are entitled to receive at university.

Empowering disabled students

Disabled students need to be empowered to speak out about the barriers they face and funding bodies have a duty to listen to disabled people's views and involve them in the decision making process.

Universities, social services and local authorities should work together with disabled students to achieve better access and to maximise their opportunities for the future. Disabled students should be at the heart of everything and they need to be involved.

Funding issues

More disabled people should be made aware of, and therefore have more access to, individual budgets.

Disabled Students' Allowance (DSA) should be included within individual budgets⁸ so that students with care packages do not have to deal with separate awarding bodies. Where it is suitable personal assistants should

⁸ In England from April 2011 the current plan is to introduce personal budgets across England. (see more details on page 22)

be able take on academic support such as note-taking and joint funding should be available.

All disabled students should have the choice whether they receive direct payments or delegate their local authority to administer their care packages for them.

Disabled students who choose to have direct payments should be given more support in learning how to employ and manage their own staff.

Portable care packages

Under human rights legislation disabled people have rights to independence, equality in education and freedom of movement. Local Authorities have a duty to ensure these rights are upheld and so disabled students should have portable care packages which meet their needs and give them the freedom to move between areas without fear of losing support.

When moving, the living expenses and pay rates in the new area should be taken into account where funding responsibility remains with the home authority.

Improvement in available data

There needs to be accurate information collated on the numbers of students receiving personal care packages. We need clear statistics about how many people are receiving personal budgets and how many of them are direct payment users, in order to provide a coherent picture of the current situation.

Clarify the law

The funding responsibilities of health authorities, universities and social services need to be clearly defined in relation to personal care and support of disabled students in higher education. More research is needed regarding students' rights to support.

The law should be focused on ensuring that people are involved in the whole process and give clarity on the provision of services.

Assessments

Local authorities should ensure that assessments support the needs of the person rather than elicit the absolute minimum level of care that can be offered. The assessment procedure should be personalised and focused on need rather than the numbers of times certain tasks are performed.

Disabled people should be on the assessment panels and a more holistic approach should be adopted that focuses on the individual need of the student.

Access to 'the student experience'

NUS should campaign to ensure care packages take into account students' need for a social life.

Social services departments and universities

It is crucial that social services and universities provide proper support for disabled students in halls to ensure full compliance with fire safety rules. They should work together to reach a compromise when responsibility for support is unclear. Any existing guidance on the issues of liability should be identified, given to the institution and followed. If there are no rules or the law is not clear then further clarity needs to be sought.

Social services could provide universities with a 'support assessor' to aid processing of care packages or use a national support assessor to process care packages.

Universities and access

Universities need to be given training by disabled people on the social model of disability and should ensure that all kinds of rooms are made accessible for everyone.

Universities should follow the Equality Challenge Unit's guidance on inclusive design.

Disabled students should not have to pay for their personal assistants' rooms. If they are not able to obtain funding then the rooms should be provided by the universities in accordance with their duty under the DDA.

Introduction

Current legislation and policy affecting disabled people who use personal care packages has been developed with the aim of reducing the inequality between disabled and non-disabled people. Despite this, research suggests that barriers to achieving better personal care packages for disabled students still exist.

This report is the result of a qualitative study into the experiences of disabled students in higher education who use personal assistants. It was carried out by National Union of Students (NUS) between September 2009 and March 2010.

The aim of the research was to build upon quantitative data collated by other charities and organisations for disabled people. All participants in the study were disabled and were either presently studying at, or had graduated from, university. People were interviewed about their experience of personal care packages and using personal assistants (PAs). The data was analysed using thematic analysis.

Current statistics do not provide a comprehensive picture of disabled students in higher education who have personal care needs. In 2010, according to the Department for Culture, Media and Sports, there are 10 million disabled people in the UK.⁹ In 2008/09 there were 86,000 disabled people receiving direct payments in England with another 3,017 in Scotland.¹⁰ In the same year, according to the Higher Education Statistics Agency (HESA), the number of disabled students receiving

⁹ Department for Culture, Media and Sports (2010) *Legacy plan for disabled people to improve the lives of 10 million in the UK*, available at www.culture.gov.uk/reference_library/media_releases/6757.aspx/

¹⁰ <http://www.communitycare.co.uk/Articles/2010/04/07/114232/Backing-for-Scots-plan-to-make-direct-payments-default.htm>

personal care support attending university was 95. This figure is collected from information provided by higher education institutions to HESA.

The NUS believes that students are often reluctant to declare a disability and that there is confusion about what personal care actually means and therefore it is possible that there is an under-reporting of need. Thus the numbers of disabled students receiving a personal care package may be greater than shown in the current statistics.

Qualitative data analysis allows for a more in-depth interpretation of results compared to quantitative data analysis techniques. We conducted 13 interviews and many of the students interviewed reported similar experiences and barriers. Although statistics on the number of students using care packages are not conclusive we believe that other disabled students would report similar findings.

The report is in two parts. Part One explains why the study was undertaken and outlines government policy and previous research. It also highlights barriers to full inclusion in education. Part Two describes and analyses the main findings from 13 in-depth semi-structured interviews with disabled students who have care packages.

The report focuses on students' personal experiences of using personal care packages while applying to and attending university and identifies the main barriers that they face. It allows the students to talk about the improvements that they think are necessary. The NUS is committed to ensuring that students get a high-quality experience of university life.

Part One

Background

National Union of Students' Disabled Students' Campaign

National Union of Students (NUS) Disabled Students' Campaign believes that lobbying for disability rights should be at the forefront of the political agenda in the UK. We work to ensure that disabled students' voices are influential in improving both policy and practice.

The NUS Disabled Students' Conference in February 2009 voted to undertake a research project into disabled students' experiences of using personal care packages, with a view to identifying the barriers to participation in higher education. The research will inform the NUS Disabled Students' Campaign 2009/10 in its *Disabled students using personal assistants* campaign.¹¹

Part One of this report explains what led to the research, details the current system of providing care packages to disabled students and places this in the context of government policy. It outlines previous research and the general concerns that are often voiced about with regard to the personalisation agenda (page 27) for disabled people. Part Two presents students experiences of using personal assistants at university and suggests ways of improving the current system.

The research methods and interview transcript are in the appendixes.

¹¹ NUS (2010) *Disabled Students' Conference (2010)*: Report , London: NUS, available at www.officeronline.co.uk/disabled/277262.aspx

Purpose of the research

The NUS Disabled Students' Conference in February 2009 heard about students with 'personal care packages', who often find that they have to challenge a system that is fragmented, complex and bureaucratic, whether they attend university in their home area or have to renegotiate personal care packages when they move to a new area.

Students were worried about being unable to get adequate and consistent care when they go away to study or move in and out of halls of residence; their rights, such as privacy and freedom from degrading treatment, are often undermined. Their vision was to be free to move without fear that they would lose their personal care package and they called on the NUS Disabled Students' Campaign to change their experience of using support services.

Past research in the area of personal care has generated overall conclusions demonstrating the success or otherwise of the personalisation programme. To be able to bring the general picture to life the NUS Disabled Students Campaign has carried out qualitative research into the experiences of students with care packages and asked them what improvements they would like. This is especially important given the proportionately low numbers of disabled students currently going into higher education.

Disabled students' academic and social care funds

In order to understand the service available to disabled students it is important to explain how it is structured and funded. There are two sources of funding to help disabled students cover their academic needs and social care requirements: the Disabled Students' Allowance (DSA) and personal care packages – funded by the National Health Service (NHS) and local authority social services.

This paper explores this funding and other sources of funding that may be available. It sets out how students might get access to DSA, personal care packages, direct payments, personal budgets and Independent Living Fund (ILF). It looks at why the academic and social care funds are funded separately at present, discusses proposals for the implementation of personal budgets in April 2011 and considers how DSA can be used in conjunction with other funding.

Disabled Students' Allowance (DSA)

In addition to the funding available to all students involved in higher education, disabled students can claim extra funding – Disabled Students Allowance (DSA) – to ensure that they have equality of access to take part in university studies. This support is available to disabled students with a wide range of impairments, not all of whom will require personal care. The amount awarded depends on what sort of support they require and could include:

- specialist equipment relating to academic studies;
- non-medical helpers (these are assistants who provide support that is not related to personal care, such as a sign language interpreter, note-taker or reader);
- additional travel costs for disabled students who face travelling difficulties from home to university;
- other costs – for example, tapes or Braille paper.

In 2008 in England DSA funding for non-medical personal helpers was increased to a maximum of £20,000 a year for full-time undergraduates. In addition students can claim for purchasing equipment up to a maximum of £5,161 over the duration of their course. For postgraduate students in England the maximum claim is £15,390 a year pro-rata to fund non-medical helpers. In Scotland undergraduate and postgraduates get the same rates.

Each of the four nations of the United Kingdom has its own awarding authority for DSA:

- Student Finance England;
- Student Awards Agency for Scotland;
- local authorities in Wales;
- Education and Library Board in Northern Ireland.

Students on courses related to healthcare can also apply for help from the National Health Service. They must apply to the relevant awarding body and supply evidence of their disability. If the application is not accepted they have to go for a diagnostic assessment of their disability. Once their evidence has been accepted they are sent for a needs assessment by a DSA assessor before the awarding body agrees to release funds.

Personal care packages

Personal care packages are the services that local authorities provide to disabled people (including students) who need care. When a disabled person requires personal care, the local social services department carries out a health and social care assessment, which should focus on an individual's needs. Health and social services teams then put together a personal care package, which may include healthcare, equipment (a hoist or a wheelchair, for example) or personal assistance.

Personal assistants, who are employed either by the local authority or the disabled person directly (see below), carry out the care component of the package, which may include:

- domestic duties (cooking, cleaning, shopping);
- personal hygiene;
- transport;

- basic medical needs (such as injections).

The value of the care package depends on a person's income. It is reviewed every year and is funded via a 'personal budget' – explained below. The package is supposed to meet all the person's care needs, although this is not always achieved, as we shall see later.

Personal budgets

When disabled people receive an allocation of funding after an assessment of their personal care needs, the money is known as their personal budget. The personal budget is used to buy the care package and the recipient has three options. They can:

- have the budget paid directly to them (direct payment, see below);
- leave the responsibility of commissioning and paying for services with the local authority;
- have a combination of both of the above.

In England from April 2011 the current plan is to introduce personal budgets across England.

Individual budgets

Unlike 'personal budgets' these incorporate a number of funding streams:

- adult social care – personal budgets including those received via direct payment;
- Supporting People – a programme of housing-related support housing related support to help people, including those who need personal or medical care to live as independently as possible in the community;¹²

¹²

http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/SupportedHousingSchemes/DG_4000297

- Disabled Facilities Grant – a local council grant to help towards the cost of adapting your home to enable you to continue to live there;
- Independent Living Funds;
- Access to Work (applicable to students who are also in employment and need support in the working environment);
- Community equipment services.

At present DSA has not been included in the list above, although this is something that may change in the future, and students who need support might still be provided for under two systems administered by separate bodies.

Direct payments

A disabled person's personal budget can be paid directly, enabling the claimant to purchase services for themselves. The Community Care Act 1996, and the subsequent 2003 regulations, requires local authorities in England to offer direct payments to users of community care services (except those who lack the capacity to control such payments). People receiving direct payments take on the responsibility of employing people and dealing with tax and national insurance. This has been the 'typical' way of students getting personal care.

The Independent Living Fund (ILF)

The Independent Living Fund (ILF) is a central government fund: disabled people who receive personal care that costs over £340 can apply to the ILF and receive up to £455 a week extra. They have to pay £80.70 a week from their other benefits (such Disability Living Allowance (DLA), Incapacity Benefits and Income Support) in order to receive this. Recent changes in the eligibility criteria mean that new applications will only be accepted from people who are in more than 16 hours per week paid employment.

Additional funding

Students who have expenses for which they cannot get funding from any other source may apply to charities. Students, for example, who have been unable to get the personal assistants' accommodation funded while at university have successfully applied to the Snowdon Award Scheme for money to meet some of the expense.

Legislation and policy

Legislative background

There are several pieces of legislation that have a direct impact on students who use personal assistants (PAs). Some of this was introduced at the end of the last Parliament and how it will be implemented will depend on the decisions made by the new coalition government.

Realistically, given the current economic climate and the well publicised intention of the new government to make cuts across the board, much of the legislation will not have as much as positive impact as had been anticipated.

The Disability Discrimination Act (DDA) 1995 was a watershed in the official view of disabled people. It began by offering protection from discrimination in employment and placed a duty on employers to make reasonable adjustments to the workplace. The Special Educational Needs and Disability (SENDA) Act 2001 then extended these provisions to further and higher education institutions.

In 2006 a Disability Equality Duty (DED) was introduced, requiring public bodies to actively promote equality of opportunity for disabled people and placing the responsibility for disabled people's inclusion firmly on public organisations. In education, the bodies responsible for disabled people's inclusion are the learning establishment concerned – school, college, university, and so on. Other laws besides the DDA and the DED, for

example the Human Rights Act, can protect disabled students' rights in education.

In order to ensure that the DDA is successful in addressing inequality government committed itself to a strategy of improving life chances with the aim of achieving equality for disabled people by 2025 and introduced the policies and legislation outlined below.

Equality Act 2010

The intention of the Equality Act is that it will replace the DDA and equivalent legislation relating to gender and race. In October 2010 the Equality Act's main provisions will come into force and the rest will follow in stages up to 2013.¹³

Disabled people and human rights

In the past 50 years the UK has introduced law, and become a signatory to a number of treaties, all of which protect the human rights of its citizens. These steps offer a framework for the protection of the rights of disabled students. All local authorities have duties to promote human rights.¹⁴ However, awareness of them is low.

The Human Rights Act 1998

The Human Rights Act (HRA) 1998 was introduced as a means to effectively incorporate the rights enshrined in the European Convention on Human Rights, (established after World War 2) into UK law. It came into force in October 2000.

¹³ See the website of the Government Equalities Office:
<www.equalities.gov.uk/equality_bill.aspx>

¹⁴ The United Nation Conventions on the Rights of Persons with Disabilities – (through the Human Rights Act 1998)

The UN Convention on the Rights of Persons with Disabilities (CRDP)

The United Nation (UN) Convention on the Rights of Persons with Disabilities (CRDP) was launched by the UN General Assembly in December 2006. The UK ratified the convention in June 2009 and, as such, affirmed its commitment to:

"...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"¹⁵

as laid out in the purpose section (article 1) of the convention. Articles 4 - 32 detail the rights of disabled people and the obligations on those states that have signed up to the Convention. Of particular relevance to students who use personal care are:

- Article 10: The right to freedom of expression requires that disabled people access to independent advocacy.
- Article 18: Moving around states that disabled people have the right to decide where they live and to move about the same as non-disabled people.
- Article 19: Independent living states that disabled people should have the right to choose where, and with whom they live. Disabled people should be provided with a full range of personal care assistance and community support as they require.
- Article 24: Education requires that disabled people be given full and equal rights to an education.

So, as a means to give context and add authority to any NUS disabled students' campaign, the UN Convention on the Rights of Persons with

¹⁵ <http://www.un.org/esa/socdev/enable/rights/ahcstata1sevscomments.htm>

Disabilities is of great value. However, ratification alone does not mean disabled people will enjoy the rights contained in the legislation and the extent to which it is implemented by the new government will be of paramount importance.

The Equality and Human Rights Commission (EHRC)

The Equality and Human Rights Commission (EHRC), the independent statutory public body for equalities and human rights, was established in October 2007. It has power to take legal action on behalf of individuals, to carry out formal investigations into discrimination and to enforce compliance by public authorities with their duties to promote race, disability and gender equality.

In the EHRC report, *From Safety Net to Springboard*, the Commission has listed a number of the social and care reform proposals directly relevant to the NUS's campaign on disabled students' experience of receiving care packages. These include the portability of care packages, making available services and information to everyone who seeks it, the emphasis on preventative interventions and on promoting choice and control and the further personalisation and 'joining up' of services.

Personalisation agenda

The Labour government's vision for 'personalisation' (personalisation means that public services are delivered via methods that provide more choice, responsibility and control for the person using the service)¹⁶ was set out in the *2007 Putting People First* report. Its goal was to promote independence for disabled people and others and to make personal budgets an effective reality, by establishing direct payments, personal budgets, individual budgets and 'Right to Control' schemes.¹⁷

¹⁶ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

¹⁷ Ministers, local government, NHS, social care, professional and regulatory organisations (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*: London: HM Government

In 2007 local authorities were required to begin putting the *Putting People First* programme into practice. They were expected to provide information on personal budgets to users and promote their take-up between 2008 and 2011. There was a 30 per cent target for take-up of personal budgets and by April 2011 local authorities are expected to have evidence that they are personalising services.

The Welfare Reform Act 2009 and the 'right to control'

The Welfare Reform Act 2009 (for England and Wales and Scotland, but not Northern Ireland) introduces, among other things, a right for disabled people to control the public funding allocated to them in the form of individual budgets and will form the basis of a 'national care service'. It became law in March 2010. The details of how this will be introduced and funded are unclear.

The new government will have the job of making sure that the new service is deliverable. It is possible that, although the policy received cross-party support, some provisions may be weakened in order to save money. From late 2010 the Welfare Reform Act's section on the 'right to control' will be piloted in eight 'trailblazer' local authorities around England. This would grant disabled people a 'right to control' how services are provided for them, which may involve them receiving direct payments in areas where they are currently not available, including for further education and training, and services to secure or maintain employment. The 'right to control' is seen as a major step towards disability equality by 2025.¹⁸

The Personal Care at Home Act 2010

This Act entitles everyone in England to free personal care at home (this has been available in Scotland since 2002). However, due to concerns

¹⁸ Office for Disability Issues (2010) *Right to Control - The Right to Control will be a major step toward achieving disability equality by 2025*, available at www.officefordisability.gov.uk/working/right-to-control.php

about the cost of the legislation the new coalition government has decided not to implement the Act and any future implementation would require a vote in both Houses of Parliament. Instead it has announced an intention to establish an independent commission on the funding of long-term care and to concentrate on rolling out personal budgets and increasing the take up of direct payments.¹⁹

'National care service' (NCS)

One of the main proposals in the 2009 Welfare Reform Act is a 'national care service' (NCS) for adults living in England. Due to a House of Lords amendment the exact nature of the national care service was made subject to further parliamentary approval after the May 2010 general election. The current proposal that after 2015 care and support would be free at the point of contact and people would have more choice/control is likely to be a subject of debate by the commission on the funding of long term care.

Progress since the Disabled Persons Act 1986²⁰

In March 2010 MPs discussed disability policy and progress on disabled people's services, consultation and representation since the passing of the Disabled Persons Act 1986. Speakers stressed that disabled people should no longer be seen as the passive recipients of services from local/health authorities but should be central to shaping services within 'the personalisation agenda'. The new legislation was seen as enabling disabled people to assert their rights and ensuring that they received their rights as equal members of society. The importance of advocacy services and consultation with organisations of disabled people in redressing this issue was stressed.

¹⁹ www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_116236

²⁰ House of Commons (2010) 'Disability Policy (Economic Downturn)' *Hansard* 23 March
<www.publications.parliament.uk/pa/cm200910/cmhansrd/cm100323/halltext/100323h0004.htm>

Clearly, the current emphasis on controlling expenditure will directly affect disabled students with a care package. It is vitally important that as new policy is created, these students' views and requirements are at the heart of any developments, especially when it comes to the introduction of personal budgets and a national care service.

Self-directed support strategy in Scotland

Scotland has had free personal care since 2002 and is at the time of writing debating the Self-Directed Support (Scotland) Bill. The aim of the bill is that more people will choose to have direct payments.

In February 2010 Scotland launched its own version of England's *Putting People First* programme in the form of a ten-year strategy for 'self-directed support'. Scotland presently has proportionately a lower take-up rate for direct payments than England and has made less progress in personalising social care.

The *Putting People First* strategy had 26 recommendations to address barriers to direct payment uptake. The Scottish government cites financial reasons (the expense of providing the service free of charge) and the possibility of improved outcomes as its reasons for wanting change to the current system.²¹

Scotland's personalisation milestones differ from England in that they recommend:

- a radical increase in the uptake of self-directed support;
- a sustainable network of independent support organisations for service users;

²¹ Dunning, J (2010) 'The Scottish path to personalisation' *Community Care* 18 March, available (as *Scotland makes self-directed support central to social care*) at www.communitycare.co.uk/Articles/2010/03/15/114050/Personalisation-in-Scotland.htm>

- appropriately trained personal assistants and personal assistant employers (service users);

Devolution has led to differences in social care policy among the four nations of the UK; they have not addressed social care together. The downturn in public spending means that in the coming years they will have to learn from each other. Concern in Scotland about the cost of free personal care and how to fund it has directly influenced the delay in England in the introduction of free personalised services.

Past research

Although the number of people with personal budgets has certainly risen, and there is increasing evidence to show the benefits personalisation can bring to individuals and the wider community, uptake across England has been patchy.²²

There have been several research projects by disability organisations into the success of the government's policies on personalisation.

Personal and individual budgets

A nfp (not for profit) synergy survey commissioned by Livability and published in February 2010 found that local authorities display a lack of awareness about the new funding systems for disabled people two years after the Government set out its personalisation goals. The survey found that nearly half local authorities had no information on their websites about personal budgets and fewer than one in ten of the people surveyed

²² The Disability Information Website (2010) *Real Choice and Control - Independence and equality in the balance* – 13 March. available at <<http://disabilitymessageboard.blogspot.com/2010/03/real-choice-and-control-independence.html>>

even knew about individual budgets – for most respondents, the survey was the first time they had heard of personal budgets.²³

Most personal budget users are positive

In Control, an organisation that helps people get real choice and control, surveyed more than 500 personal budget users (most from England and of all ages) between 2005 and 2009. The findings demonstrated more than two-thirds (68 per cent) of those surveyed felt that using personal budgets improved their lives.²⁴

A survey by the Local Government Association and the Association of Directors of Adult Social Services (ADASS), which focused on the local authorities' progress on personalisation, reported a commitment sufficient to see 400,000 people receiving personal budgets by April 2011.²⁵

University Challenge survey

The Trailblazer (not to be confused with the eight 'trailblazer' local authorities piloting the 'right to control') network work of young volunteers local authorities piloting the 'right to control', part of the Muscular Dystrophy campaign (MDS), looked at disabled students' experience of higher education. They asked the UK's 100 top universities 15 questions about access and facilities. Their 2009 report – *University Challenge* – found that universities are still failing disabled students on the question of access.

²³ Livability (2010) *Personal budgets - which local authorities are ready?* 10 February – available at <www.livability.org.uk/news.asp?id=1858&detail=2>

²⁴ Mithran Samuel (2010) 'Personal budgets delivering improved outcomes', *Community Care* 16 March 2010, available at <www.communitycare.co.uk/Articles/2010/03/16/114055/In-Control-Personal-budgets-delivering-improved-outcomes.htm>

²⁵ Association of Directors of Adult Social Services/ Local Government Association (2009) *Putting People First: Measuring Progress*, available at <www.adass.org.uk/images/stories/PPF%20Measuring%20Progress%207%20May%20NA.pdf>

The report findings include:

- when choosing an university with the late summer clearing process disabled students are at a huge disadvantage–by having less than a month to find a course and check access, accommodation and care packages.
- almost half (40 per cent) of the 78 universities that responded do not have accessible accommodation and therefore disabled students are denied access to university life. For students with care packages this is even worse, if universities do not provide an extra room to accommodate the personal assistant.²⁶

The survey found that many disabled students experience some form of access barrier that can range from failure to access benefits through to mismanagement and opportunistic exploitation.

So far research – as described in this section – has generated overall conclusions about the success, or otherwise of the personalisation programme. Our NUS research, however, examines students’ experiences of a personal care package and gives a detailed picture of the practicalities of using personal assistants in higher education.

Barriers to the personalisation agenda

The personalisation of services is an important current political goal and the new government has announced that it is committed to continue with the agenda. In what is seen as an underfunded social care system, however, there are concerns about barriers to achieving it and about possible difficulties that it may create for some disabled people.

²⁶ Muscular Dystrophy Campaign (Trailblazers) (2009) *University Challenge Report 2 of the Inclusion Now campaign*. Available at [University Challenge](http://www.mdctrailblazers.org/assets/0000/3300/Trailblazers_education__29C.pdf), <www.mdctrailblazers.org/assets/0000/3300/Trailblazers_education__29C.pdf>

There are several factors that could undermine the benefits of personalised services for disabled students:

- financial concerns about amounts that students receive in the DSA;
- watering down of the reality of the 'right to control' and personal budgets;
- individuals' different levels of capacity for dealing with direct payments;
- direct payment users' varying ability to deal with employing personal assistants;
- the failure of universities to provide access for disabled students;
- local authorities' emphasis on cutting costs resulting in reduced choice;
- those who are not in employment for 16 hours or more per week can no longer apply to the Independent Living Fund (ILF) as new applicants;
- the Personal Care at Home Act will no longer be implemented, because of the new government's financial concerns;
- there are proposals within the Conservative Party to replace the Human Rights Act 1998 with a new Bill of Rights

Financial concerns

NUS is concerned that many disabled students do not receive money to which they are legally entitled – either because they are not informed about the benefits available or because of mismanagement and opportunistic exploitation.

Problems with Disabled Students' Allowance (DSA)

Current DSA regulations say that students can choose any supplier of equipment that they want. The opportunity to choose is not always made clear to them. Sometimes Student Finance England (or the equivalent administering body of DSA in Wales, Scotland and Northern Ireland) does not approve more expensive equipment if assessors have provided cheaper quotes, even when the students have other reasons for preferring different suppliers.

Student Finance England (the Students' Loan Company) took over responsibility for administering DSA from English local authorities in 2009. In April 2010 Student Finance England was criticised, by the NUS and others, for its mismanagement of DSA. By March 2010 only 10,363 of the 22,112 disabled students who had applied for their DSA before they entered university in September 2009 had received any payment.²⁷

The inadequate administration of DSA has meant financial hardship for disabled students and in some cases for equipment suppliers, support workers and assessment centres.²⁸ It has increased the administrative burden on universities' disability offices. DSA is just one part of the package of financial support available to disabled students; if this part of the system goes wrong then it may hamper a student's ability to get access to other forms of help with their studies.

Students denied access to university campus

It is not clear who is responsible for funding the cost of providing accommodation for the disabled students' PAs. It is clear from the steady and significant increase in the number of disabled students applying to the Snowdon Award Scheme (a charity) for funds to cover their carers'

²⁷ Tariq Tahir (2010) 'Funding delays hit disabled students' *The Guardian* 6 April, available at <www.guardian.co.uk/education/2010/apr/06/disabled-students-allowance-delays>

²⁸ <http://news.bbc.co.uk/1/hi/education/8495290.stm>

accommodation and/or for the cost of adapted or accessible accommodation on or close to campus, that this is a growing problem.²⁹

Disabled Students' applications to the Snowdon Award Scheme for accommodation costs

Academic Year	Carer's accommodation	Other disability-related accommodation costs	Total accommodation related applications	Total of all applications to Panel	Accommodation % of total applicants
2005/6	1	1	2	87	2.3
2006/7	3	3	6	120	5.0
2007/8	2	4	6	109	5.5
2008/9	5	7	12	122	9.8
2009/10	5	8	13	121	10.7

Individual budgets

The Equality and Human Rights Commission (EHRC) has warned that individual budgets should not be seen as the only way to pressure for a move to personalised services. It acknowledges that traditional models of service provision were outdated and that offering users of services more independence should be welcomed. However, it warns, there is concern about the current economic climate and how this may affect budgets and in turn the 'right to control'.³⁰

Delay to the 2009 Welfare Reform Act

The decision to delay the implementation of the Welfare Reform Act was due to local authorities' worries about funding and delivering personal budgets. Local authorities argued that they cannot deliver the personalisation agenda during 2009/2010. Unison, in their role to protect employees, maintain that services must be available, accessible and not

²⁹ <http://www.snowdonawardscheme.org.uk/grants/>

³⁰ Equality and Human Rights Commission (2009) *Personalised care services ... who knows best? Equality and progress or choice for the few* (EHRC's responses to Labour Conference 2009 Fringe) Dehavilland, available at <http://www.dehavilland.co.uk/Verticals/userlogin2.aspx?ReturnUrl=%2fVerticals%2fMonitor%2fMoStart.aspx%3fitems%3d17644205&items=17644205>

open to exploitation from local authorities; it says that people who do not feel happy to manage their own budgets and take on employees should be given other choices.³¹

Capacity to handle choices

The NUS wholeheartedly welcomes disabled students being given more power to influence and choose the provision of services that are essential to ensure their equality with non-disabled students. Any system must incorporate choice in order to meet the needs of a wide range of individuals. The Equality and Human Rights Commission's (EHRC) has pointed out that people have different levels of capacity to manage choices, arguing that for some people will need independent advocacy and support if they are to make effective choices.

The EHRC also argued that, to ensure that individual's rights are protected, the market with regard to care staff must be regulated. The Disability Trust stated that those who do not want to control their budgets, or lack the capacity to do so, must be catered for. They also called for personal assistants who work with disabled people to be monitored for their suitability.³²

Access to higher education

In 2009 NUS research into disabled students' participation in further education found that many disabled students in further education were not progressing to higher education.³³ Colleges were inadvertently

³¹ Hilary Land and Susan Himmelweit, (2010) *Who cares: who pays? a report on personalisation in social care prepared for UNISON*: London: Unison, available at <www.unison.org.uk/acrobat/19020.pdf>

³² EHRC's responses to Labour Conference 2009 Fringe (2009) – *Personalised care services ... who knows best? Equality and progress or choice for the few*: Dehavilland, available at <http://www.dehavilland.co.uk/Verticals/userlogin2.aspx?ReturnUrl=%2fVerticals%2fMonitor%2fMoStart.aspx%3fitems%3d17644205&items=17644205>

³³ NUS (2009) *Finding the way in FE – Disabled students' participation in further education*: London: NUS, available at <http://resource.nusonline.co.uk/media/resource/Full%20report%20-%20disabled%20students'%20participation%20in%20FE.pdf>

encouraging the 'revolving door' scenario, taking on a 'social care' role for disabled students, rather than encouraging them to move up to higher levels of education or employment. Lack of access for disabled people in many universities³⁴ and worries about funding and the bureaucracy involved in arranging personal care also deter many people from progressing to higher education. In order to avoid curtailing students' aspirations, they need real choices and adequate levels of support.

Independent Living Fund (ILF)

From May 2010 new applications for support will only be accepted from those working for more than 16 hours per week in paid employment. Previously, applications were also permitted from those receiving significant levels of social services support with income-related benefits.

This move could be seen as undermining Article 19 of the UN Convention on the Rights of Persons with Disabilities (living independently and being included in the community). These new restrictions to eligibility for the ILF could threaten the ability of disabled students to live independently, and create a barrier to disabled students' right to choose where they live.

Personal Care at Home Act 2010

The new coalition government has decided not to pursue Labour's Personal Care at Home Act. This could have a negative impact on disabled students' human rights as the proposal that under the Act care packages would be made portable will not be implemented and thereby the right to

³⁴ Muscular Dystrophy Campaign (Trailblazers) (2009), *University Challenge* Report 2 of the Inclusion Now *campaign*. Available at [University Challenge](http://www.mdctrailblazers.org/assets/0000/3300/Trailblazers_education__29C.pdf), <www.mdctrailblazers.org/assets/0000/3300/Trailblazers_education__29C.pdf>

liberty of movement under Article 18 of the United Nations Convention on the Rights of Persons with Disabilities could be restricted.

Human Rights Act

It is not yet known what impact the change of government will have on human rights legislation. However there are signs of a desire, at least within the ranks of the Conservative Party, to repeal the Human Rights Act and replace it with a British Bill of Rights. The new government has announced a commission to review the Human Rights Act.

Students with personal care packages

The core of this research is disabled students' experiences of using personal care packages and how their real experiences compare with the aspirations of government policies. The Personal Care at Home Act could have been an important tool for ensuring that issues that directly affect students, such as time lapses between assessments when moving, inconsistent services, or delays in the provision of care packages, are considered when developing new policy and practice (the 'national care service', for instance). Unfortunately, the Act has been discarded by the new 2010 coalition government and, although it is expressing support for the personalisation agenda and for direct payments, a vital opportunity to improve the services available to care users has been missed.

The personalisation of services and the crucial issue of protecting the rights of disabled people need to continue to be high up in the political agenda. The introduction of the 'right to control' and personal budgets have implications that directly affect disabled students and our investigation of students' experiences shows how current policy can affect their academic and social lives and their personal well-being.

Another option is to use existing human rights legislation to protect students' academic and social lives and their personal well-being.

NUS wants to see personal budgets made more accessible for disabled students. Without the full implementation of personalised services, disabled students will not have access to education and society that they have the right to expect.

Part Two

Interviews with disabled students in higher education

The second part of our report presents the key findings and recommendations from our interviews with disabled students. Despite coming from a variety of backgrounds, students related strikingly similar experiences of the administration of their personal care packages. The following themes were identified in the interviews:

- choosing a university/course
- starting at university
- support provided by universities
- inadequate assessment procedures
- inconsistent services from care agencies
- Courage and capacity: fighting for good services
- effect on students' university experience.

2.1 Choosing a university/course

"Every student has the right to make their choices of university, based on academic and social concerns rather than because of the practical facilities available ... It is vital to ensure all students have access to the same opportunities" (Philip Butcher, of the Muscular Dystrophy Campaign, 2009)

How do disabled students choose a university and how does having a personal care package affect their decisions? In general, our interviewees found that universities' literature advertises courses that they claim to be accessible. Students make their choices on the basis of this information;

only when they arrive at university do many discover, for example, that the accommodation is not accessible.

"I was not told until at the university and about a week into the course that my department was up two flights of stairs."

Many leading institutions have traditionally built, inaccessible buildings. Several disabled students that we interviewed reported having accepted places at less prestigious institutions, solely because of this lack of access.

Most interviewees said that access was paramount and that they chose the university with the least barriers.

Typically, students explained:

"Most of the colleges are not very forward thinking towards disability. I picked the best college of a bad bunch as it has the best accessibility."

The NUS Disabled Students campaign believes that disability is socially constructed – it is the result of society's inability or unwillingness to accommodate people with impairments. Thus accessibility is of prime importance and the interviewees' responses demonstrated that they regarded it as essential to attend somewhere accessible.

Although most universities' literature claimed that services and facilities were accessible the reality fell far short.

"I chose X as I thought it was my only choice. I had the option to go to Y but they had a complete lack of access, which made it impossible for me to go. X seemed better and more accessible. Unfortunately, X did not have the experience of setting up care packages though, so I had to sort it out through my social worker."

The quote shows that even if universities follow, or aim to comply with, the DDA 1995³⁵, which stipulates that universities must make reasonable changes to their premises to make them more accessible, when faced with a disabled person who requires a personal assistant they seem unable to provide true access.

Most interviewees were forced to choose the best of what they regarded as mediocre choices on offer; several reported being unable to attend more prestigious institutions because of worries about access.

Work placements abroad

Some people told us that they had been deterred from applying for universities that offered placements abroad because of fears that the barriers to arranging support would be insurmountable. One interviewee said:

"In a way my course is perfect for me as it is one of the only language courses in the country where you do not need to take a year off abroad. I thought I would probably struggle with this aspect because of my care package. I also do not have to undertake any work placements. However, if I needed to do this then I think my university would be very good at supporting me. If they did not, then I would certainly speak up about it."

One student had been turned down by her chosen university because her impairment was becoming more severe and although she wanted to follow a course that included a work placement abroad the financial implications of her carer accompanying her prevented her doing this.

³⁵ Disability Discrimination Act 1995

"I wanted to do medicine but got turned down because they knew my disability was going to worsen. Instead I decided to do psychology. In my third year I wanted to do a mandatory year-long placement abroad (it didn't have to be abroad but I wanted to go abroad) – however, I couldn't because I couldn't get funding for a carer to accompany me abroad."

Disabled students with personal care packages, our interviews showed, experience a lot of indirect discrimination when it comes to choosing a higher education course. Research by the Muscular Dystrophy Campaign (see page 32) confirms the extent to which universities are failing to provide access for disabled students.

Students who cannot or do not want to live at home have to select a university that can accommodate them and their PAs. This, together with the difficulty of arranging personal care shows why so many disabled students are put off progressing to higher education.

This is intolerable in the light of current equality and human rights legislation. While non-disabled students are making choices based on the content and quality of the course disabled students maybe deciding where to study merely on the basis of whether the lectures are on the ground floor. Similarly, non-disabled students choose universities based on where their friends are studying and what the local area has to offer, whereas disabled students with personal care packages are having to consider whether there is information on personal care available and the attitude of the local authority.

2.2 Starting at university

Starting at university was one of the main periods that interviewees talked about. Everyone we spoke to felt that it was very important to get support right from the start and that without it in place they could not access everyday student life. However, people reported not knowing how to get information, advice and guidance (IAG) about support or equipment. Often it appeared that information given in one part of the country did not apply when they moved to a new area.

The lack of information shows the needs for an awareness campaign about services available, policy relating to personalisation and human rights legislation, to ensure that disabled students are fully aware of the services they are entitled to at university.

Several of the interviewees felt that the care package they received during their time in a further education or 6th-form college had allowed for more flexibility and was therefore easier to manage and less bureaucratic. They attributed this to the fact that higher education funding systems are split between academic support – funded through Disabled Students Allowance (DSA) and administered in England by Student Finance England – and personal care – awarded by the local authority. Having two discrete sources of funding for needs arising from their disability and separate responsibilities on the institutions to provide accessible buildings created more uncertainty and affected their studies. It may also have deterred some people from even applying to higher education. Theoretically personalisation and a 'national care service' could improve matters, although as the DSA is going to remain a separate funding source the system will remain fragmented.

When considering the transition to university it is important to distinguish between two groups of students: those who receive a care package from their local authority (page 46) and those who have to renegotiate their care package because they are moving to a new area (page 48).

2.3 Students attending university in their home area

There was no-one in our study who had not experienced problems in the process of getting to university. People faced difficulty, whether they were remaining in their home area, where they were already receiving a care package from the local authority, or moving away from home and therefore changing local authority.

Students already receiving a care package from their local authority but wanting to attend university in their home area still experienced barriers. The most commonly identified were:

- lack of information, advice and guidance (IAG) about who should be responsible for providing care services
- lack of clarity between social services and universities

Lack of information, advice and guidance (IAG)

Several interviewees had found themselves caught in the middle of an argument between the university and social services over certain areas of funding, for example, for paying for a personal assistant required because buildings were not accessible. Such experiences left them feeling unsure about the feasibility of attending university.

One student said it was like being in a 'tug of war' and had felt so overwhelmed that he could only 'leave the two of them to fight it out amongst themselves'. The worry over what would happen if he did not get funding or if funding was later withdrawn left him questioning whether he really wanted to study.

"I do not have enough (support) and ideally I would like more. However, I am very aware that many disabled students receive less support so I believe I get a fair share of what is currently available".

Disabled participants expressed the desire to have access to the same experience as their non-disabled peers, but their worries about their need

for support prevented this. The barriers they faced included moving into halls that had not been adapted, navigating a new city that was not accessible, and starting university while still struggling to get support needs recognised and funded.

Lack of clarity between social services and universities

Many interviewees reported confusion among those responsible for providing personal care support – or different elements of it – at university. One local authority, for example, argued that the university had accepted the disabled student knowing her needs and, therefore, should be responsible for making reasonable adjustments (under the DDA 1995) for her while at university. The university insisted that social services should pay for any care because DSA only provides for support directly related to academic study.

One interviewee's social worker had never dealt with a disabled person with care needs wanting to go to university; she too found herself in the middle of a battle between social services and university over who would pay for support. She commented that she "*should not have to deal with that*".

Another student who was moving between halls found that the fire safety rules had been tightened and it was now necessary that all students could evacuate halls in four minutes. This would have been problematic for the student at night as he had no PA and the hall management could not accept him unless he could guarantee to be able to get out of the building in four minutes. Thus, in order to be able to live in halls, he would need 24-hour PA cover. The local authority refused to pay for this level of care (£52,000 a year) and argued that, as the stipulation arose from university policy, the university should pay. The university argued it was a fire safety requirement and it is not responsible for the cost of personal care of any student. In the end the university stated they could not accept the student without a guarantee of cover.

Another student reported:

"...[I was receiving] direct payments for the carers' actual pay although it wasn't clear who had to fund all the other costs. I soon found out that I had to pay the carers' rent, food and transport. I receive assistance from the Snowdon Award and housing benefit to pay for two of the three rooms but even these two [sources of funding] don't cover the full cost of those rooms and I also have to pay another room".

Problems of this kind with the costs of accommodation were widespread and are corroborated by the Snowdon Award Scheme's research (page 36), demonstrating that this area requires further examination and improvement.

Disabled people have a right to live independently in the way non-disabled people take for granted. There is now more awareness about disability and discrimination: the personalisation agenda, direct payment, and equality and human rights legislation are all helping. However, to achieve equality for disabled students and give them full access to their rights changes to the present funding systems are needed. There needs to be consideration given to how students with personal care needs will be affected while DSA remains outside individual budgets.

2.4 Renegotiating care packages

Under Articles 18 and 19 of the United Nations Convention on the Rights of Persons with Disabilities students should have freedom of movement, if the obstacles involved in arranging care packages restrict this freedom then this is in direct contravention of their rights.

We found, however, that students who move to a new area for their higher education hit additional difficulties in starting at university when they had to renegotiate their care packages.

Several students that we talked to had experienced a delay in receiving care because of problems associated with the transfer of responsibility for care provision from one local authority to another. Given that the needs of some students are urgent, the issue of 'portability' of care is important. Interviewees pointed to:

- inadequate levels of support;
- students unaware of problems they may encounter;
- lack of support when transferring care package;
- lack of support from professionals for students' decision to study;
- unclear law;
- no uniformity in assessment criteria or rates of pay.

Inadequate levels of support

Several interviewees found themselves caught between two authorities with no-one wanting to accept responsibility. One student described this as like having to navigate: "*a really tough immigration policy*". He felt the new local authority did not want to accept responsibility for him. He did not need care for enough hours a week to be eligible to employ a carer through direct payments, but the lack of support affected his studies and, since his care package made no provision for social activity, his social life.

Interviewees proposed that disabled students who use care packages should be able transfer the between local authorities without having to be reassessed. They wanted portable care packages that met their needs and gave them the freedom to move between areas without fear of losing support.

Students unaware of problems they may encounter

Some interviewees had no idea that there would be difficulty in transferring their care packages from one borough to another. One, for instance, only found out about this when her family's plans to move house affected her care package.

"Last year my family tried to move a few minutes down the road, out of the borough that we live in and that funded me. Even this small distance would have brought about immense difficulties in transferring my care package as I am not aware of the system for moving my care package from one borough to another."

The interviews showed that when students are thinking about going to university they initially focus on courses they wish to study and which universities provide these without considering the practical implications of moving their care package. They soon become aware of the uphill struggle facing them.

Lack of support when transferring care package

Students need a positive attitude from social services staff in order to transfer their care package from one local authority to another. Attitudes of professionals varied tremendously: some local authorities wanted to be supportive and aid a smooth move but were restricted by the barriers within the system.

One interviewee's original local authority had provided her with a very good support. But she moved and the new local authority insisted that everything had to go through the social worker and suggested she look for support from the care agencies that they would administer. The previous local authority could not get involved as they no longer had responsibility for her. Eventually, she had her hours of care reduced and

then had to rely on friends, family and people in her halls of residence to help her.

We interviewed the friend of one student, who told us:

"Kathy is remarkable in that she met all these difficulties and overcame them. She feels, sadly, that she is unusual and that the experience of another friend, Paul, is more typical.

"Having moved from away from home to study, Paul found himself caught in a battle between the old and new local authority over who was to pay for his support. In the end, once he had secured a permanent address, the new authority took the responsibility.

The new authority has, however, only funded an inadequate 21 hours a week – with low-quality agency staff – which Paul has been surviving on for three years. On top of his physical disability, Paul's general health has deteriorated directly due to the poor quality care. He develops frequent infections due to their lack of skill and training and they only ever cook him microwave meals.

His one-year postgraduate course has now taken him two-and-a-half years and he has lost friends due to the strain placed on them to try and make up for the inadequate care. He now has mental health difficulties and has reached the point where he is too depressed to do anything about this situation."

Whereas Kathy was spurred on to fight by the inadequacies of her care, Paul, like so many others, broke down.

Paul's experience not only highlights the barriers facing disabled students when dealing with personal care packages, but also emphasises the possible barriers (discussed in Part One) to the personalisation agenda. The coalition government must ensure that all efforts to pursue the

personalisation agenda are led by disabled people and that the experiences of students with personal care needs are integral to shaping future policy and legislation

Lack of support from professionals about decisions to study

Everyone who moved to new areas reported a lack of information, advice and guidance (IAG) about moving a care package between authorities. Although some had social services staff that supported the decision to move, others described how staff had tried to convince them to stay in the same area. Sometimes staff wanted to help with the transition but was unable to do so and the new authority reassessed the disabled student, often reducing the hours of care.

Some local authorities encouraged students to stay in their area by offering them extra benefits, such as more hours for personal assistants and housing. Students were often tempted by such offers as the complications of moving outweighed their academic aspirations. One student explained her authority's attitude:

"I was the first disabled student [in my local authority] to go away to university – the social worker and the adult social care department had no idea about the type of care I required or how this was to be met ... The social worker told me that if I went away to university I was eligible for only an hour's care [a day] and that I would have to manage the rest of the time with assistance from friends. I was also told that even though I required more care from the care agency the latest service I could receive would be 8pm and was told that if I required assistance at night then I would not be able to go out".

"However, if I agreed to stay in [my home area] they promised me a council house, with carers in three times a day to assist me with personal care and then I could drive to the local (pretty poor) university and attend there. I ended up having to appeal to the health and social care board."

Interviewees wanted to see a national body with local officers administering a system of funding, similar to the Disabled Students Allowance (DSA). A crucial part of its role would be to facilitate students moving between one local authority and another. They would prefer this system to specialise in providing funding and support for disabled people with personal assistants.

Unclear law

Interviewees found frequent difficulties with getting hold of clear and accurate information, especially about the legal responsibilities of all the different agencies involved.

One student found that when she went to university her home local authority remained responsible for funding her personal care package even though her health service funding transferred to the new area. This, she said:

" ... has caused problems with things that do not fit clearly into one of the two categories. Some equipment should be funded through a different scheme but they [her home authority] have refused to work with the new authority on it."

Even greater problems arose when this student's support needs did not fit clearly into either health or social services:

"I would prefer everything to be handed over to [one authority] but they refused to take it due to the law stating they don't have to.... I have not had a problem with my PA but I have had had a problem with my equipment as the law [about who pays for equipment] is more ambiguous"

"I refused the ILF [Independent Living Fund] as the company charge £90 a week and then take nearly the entire care component of your DLA. I receive £60 a week from the DLA and the rest from incapacity benefits and income support. I would get more money for the PA if I did take the ILF but I would have so little choice therefore I would prefer to get more equipment and then wing it with ready meals!"

For similar reasons another student could not get funding for a mobility trolley and others had found that the law about who pays for equipment was unclear. They suggested that there needs to be clear information about what health and social services will fund. This requires further examination and improvement.

Differing assessment criteria and/or rates of pay

Local authorities do not have uniform criteria or rates of payment and these differences affected disabled students' care packages when moving away from one borough to another, resulting in confusion and problems with payments to care staff:

"If you have the same hours [of care] when you change areas you may not be able to pay your PA the same rates of pay as these may change."

"As the wage cost is much higher here in xxxx it has meant that I have had to put my wages up, as it is only way I can keep my staff, but I still receive the same amount of funding."

Interviewees felt several local authorities were not aware of their responsibilities and did not realise how their actions affected students' lives:

"If your old LA [local authority] is funding your CP [care package] then it is important that they take into account the living expenses of the area you move to. If the living expenses increase then your CP should increase and if they become lower than vice versa. If people in the system do not understand independent living then the social worker will reinforce this."

Some suggested that the home local authorities need to provide enough money to support the care package that the students receive when they are in a different local authority. However, from the responses, it appeared that if students were not aware of independent living then the social worker did not offer any information to increase their awareness.

It is clear that portability, fair and consistent assessment criteria, transparent decision making, appropriate IAG and being treated with dignity and offered real choices mattered very much to the interviewees. The right to freedom of movement and education is protected in the United Nations Conventions on the Rights of Persons with Disabilities and for disabled people to be experiencing barriers to moving to pursue an education means that these rights are being denied.

3 Support provided by universities

Universities do not provide personal care packages. Students get support for their academic studies via Disabled Students Allowance (DSA) and universities often employ disability and access officers. Problems arise when social services and the student's university do not agree on whether the support required is to fulfil an 'academic' or a 'social' need.

Even when a need is established the system does not work smoothly. Inadequate administration of DSA – described on page 35– has resulted in disabled students not receiving the money that they are entitled to.

Talking about university support, interviewees' concerns included:

- inappropriate support by DSA assessors;
- failures to make reasonable adjustments under the DDA;
- disagreements between universities and social services about funding responsibilities

All interviewees were receiving DSA and excellent support from their DSA assessors; they felt this support was of great benefit to their academic work.

Sometimes, however, the DSA assessor felt that interviewees care needs were not relevant to their studies and they did not get help that they felt they required.

"The DSA assessor had not dealt with anyone with a condition similar to mine or with similar needs to me and even within the assessment it was clear that she was well out of depth."

Where the DSA criteria did not cover certain needs students had to approach social services or the health authority to fund the support.

Inappropriate support

As social/medical needs are not covered under DSA, the university sometimes offered students inappropriate equipment just because it could be funded within the DSA criteria:

"The best that could be offered was to organise a mobile phone for me to call the university medical team when I needed to go to the toilet or have my nose wiped!" [as told by his additional learning needs manager]

The student *"put his foot down"*, saying that this was *"unacceptable"* and demanded constant personal care when on campus.

Even when appropriate equipment was provided universities did not always provide the facilities to support its use. For example:

"My occupational therapist found a bed which she felt would extend my ability to transfer independently into bed with a sliding board rather than hoisting – I was therefore given a grant which paid for the bed at university – however, as the room was too small we were never able to use it properly and I required a hoist within a month of being at university."

Failures to make reasonable adjustments under the DDA

Universities did not always take their legal responsibilities seriously and make the required reasonable adjustments to buildings and facilities without delay, students told us. This was especially relevant for personal care users as in order to fully benefit from their care package it was essential that basic access requirements were met. One student summed up the universities' attitude:

"The University of xxx is not used to having severely physically impaired students and does not like making adjustments for them."

Accommodation is a frequent example of universities' failure to make reasonable adjustments for disabled students, when they need alterations in bathrooms and bedrooms:

"I have been waiting almost for a year for the changes required to allow me to use my environmental controls to be carried out. I have been forced to pay in the past towards having the adaptations done as the university has given me an ultimatum of paying to get the work done and getting it over and done with fast rather than waiting an average of 12/18 months for them to get round to funding it themselves."

One student went as far as to get the head of her local social care team to write to the vice-chancellor, threatening to sue the university for constantly breaching the DDA. Only then did the university adapt the bathroom to allow her to use her hoist.

The Snowdon Award Scheme is receiving increase numbers of applications from students to help fund carer's accommodation and other expenses that neither the local authority nor the university will fund (see page 36). This may be due to either tighter budgeting or an increased number of PA users attending higher education.

Universities are not ensuring that students with PAs have equivalent access with other students' to university life. Accessible accommodation is a particularly acute problem (see page 32). Disabled students who have care packages are not getting the support from universities that they have a right to expect and therefore are receiving the equality of education that is expected under human rights legislation. Universities should be required to make sure that all students are getting equal access to education.

4. Assessment procedures

Assessments by social services of disabled students' needs are crucial in ensuring that they receive a care package. Our interviews showed that procedures varied between local authorities. Students often reported feeling they were being offered a minimum level of care, which was only improved if they were assertive and challenged the decision.

Students' concerns included:

- intrusive and unnecessary questions during assessment;
- social services offering the minimum care possible.

Interviewees had mixed experiences of the assessment process for personal care. While a few described it as 'welcome and open', other comments ranged from, 'smiley but unhelpful' and (more often) 'intrusive and unpleasant' and apparently designed to discover the absolute minimum level of care that could be offered.

Several interviewees had found that the only way to get sufficient PA hours was to stretch extent of their disability – this was in no way an attempt to defraud but was simply the only way to obtain the necessary level of support. Students agreed that assessments needed to be more personal and designed to support the needs of the person.

Intrusive and unnecessary questions during assessment

The assessment process for personal care was felt to be very intrusive, with everything explained in great detail, even things such as:

"how many times a day I go to toilet" or "how many nights in a week do you use your asthma inhaler?"

Such questions are mainly unnecessary; if you need help to go to the toilet or use an inhaler then clearly that help needs to be available when the need arises, not at set times during the day.

"I had to explain that what I did in a day in university was not rigid. It seemed that it was not viable to work in this type of schedule with a PA or an agency. They expect your life to be aggregated into a series of hours and you have to describe fully what happens in those hours."

Quantifying needs was not only impossible but unrealistic. One person explained how he experienced nosebleeds, which were both variable and unpredictable, a fact that cannot be captured by simply putting down an average number of nosebleeds a week; he simply needed 24-hour care since if the personal assistant was not available when his nose was actually bleeding he would not have the assistance he required.

Many students felt that in order to get an adequate care package, that should be theirs by right, they were forced to give the worst case scenario and pushed into fudging the truth.

The minimum care package

Interviewees were given the impression that social services' aim was to offer the minimum care package possible, saving money rather than recognising individual needs.

"The DDA states that every disabled person should be able to live the life of a non disabled person but at the moment the assessment process prevents most disabled people from doing this."

"The social services string you along a bit with a care package they know is insufficient and offer the minimum care possible, either because of lack of funds or lack of concern."

It appeared that care packages were being decided on the basis of a person's ability to be assertive rather than evidence of need. Students expressed concern for younger disabled students who may not be aware of their rights or have the confidence to fight for them.

Social workers had real problems understanding disabled students' needs and suggesting appropriate support. Agreed adaptations could take weeks or even months to be made. These inadequate levels of support compromised students' success in their courses:

"If I had a PA then I could do the dissertation in the set time frame. However due to the fact it takes me so long to get ready in the morning means that I do not get into university until around 12 and I end up wasting all of the mornings. If I had a PA then I would be ready much quicker in the morning."

With pressure on them to make savings where possible, Social services review their assessments each year. One student stated she had to ensure reliving the flawed assessment process every year as *"the social services will try to minimise the amount of support you receive"*. This is often done by asking irrelevant questions and ignores the fact, in almost all cases, the student's disability will not change throughout their time at university.

Interviewees felt that *"service users needed more guidance from independent impartial sources"* and most would like personal budgets to be made more flexible so they do not have to account for every hour of care that they need.

Differences in assessment procedures between local authorities give rise to a mixed experience of being assessed. The establishing of national standards under a national care service could improve this, but unless the service is properly funded students may still have to paint a very negative picture or behave very assertively to get an adequate care package. Given the economic stringency being emphasised by the government this appears to be a very real danger.

5 Care agencies vs direct payments

Local authorities with responsibility for providing disabled people with personal assistants often use care agencies to provide them. Levels of service and reliability vary.

The problems that interviewees told us about in connection with their care packages show why several of them preferred to employ their own personal assistants using direct payments and to contact care agencies only for emergency cover.

Poor service and unreliability

Standards of service provided by agencies, as with any business, vary. Some agencies are run by organisations of disabled people and some are administered by private business. Several interviewees speculated that the poor service they received was because care agencies were run with an eye to profits and were less attentive to providing the best service. As a result, personal assistants were often poorly-trained or uncaring of their needs. One student said:

"having PAs from abroad (I used to recruit the live-in care from the care agency, where many of the PAs were from abroad) made it difficult for me to fit in with my kitchen group and due to the amount time needed to carry out the care it meant I often missed out on social situations ... It can be very awkward with carers who don't speak English fluently as firstly it takes so much longer to explain care tasks or general 'living' tasks and secondly it is very difficult to be accompanied by someone who speaks English poorly."

Another student felt degraded by the care agencies:

"... people think 'care' is an easy career for which you need no qualifications and the care agencies are too business-focused. They 'make up their own rules' ... for example requiring me to be in bed by 11pm...The carers were often of a very low standard and seemingly untrained."

She said described one carer as constantly "smoking weed", while another was unbearably patronising. This left her so low that she had to postpone her Christmas exam and finally she dismissed the care agency without knowing where she would get support from.

Direct payments can be empowering

Some interviewees were very disappointed by the lack of knowledge and the basic lack of common sense which was shown in the social services' assessments:

"I had one social worker who ticked a box to say that I should not take direct payments as this would take up a lot of time due to the paperwork and the interviewing of staff. I think they got a shock when I said I wanted direct payments and they did not know what to do."

Although many interviewees were attracted by the idea of more personalised budgets to make things more straightforward they were worried about the bureaucracy involved. A significant number of interviewees had opted for a direct payment scheme because they wanted to be independent and employ their personal assistants themselves. One told us that having her own budget and power to recruit has been cheaper than using agency staff.

Some people prefer to use a mixture of individually recruited PAs and agency staff. They tended to use the agency staff to plug gaps, for

example to cover their carer's sickness. Several enjoying being an employer, doing their payroll, recruiting and indeed dismissing!

A student who was receiving direct payments to fund her personal assistants found this a difficult process and was only able to do it with the help from her university's access centre. Despite it not being their official role the staff at the centre helped her advertise and recruit someone; even then the process took a year.

Another interviewee stated that at 18 he made many mistakes that he would not make now and may not have if he had been given training beforehand. Overall people felt that "*service users need more guidance from independent impartial sources*" and suggested that disabled students need greater support in learning how to employ and manage their own staff.

6 Courage and capacity: fighting for good services

The disabled students that we interviewed spoke about having to challenge inadequate assessments by social services, to ensure that they received an acceptable level of care service. They felt that social services often offered them the minimum care possible, either due to a lack of funds or inability to assess the correct level of care package required. How does this affect students?

Students told us about:

- arbitrary assessment decisions
- having to challenge social services' decisions
- rights denied – for both assertive and passive students

Arbitrary assessment decisions

Social services department decisions can seem to be quite arbitrary, whether students are staying in their home area or moving away:

"When I first arrived at university I approached them through a social worker. I told them that I needed more support and a new care package. When I approached social services [a different team covering the area I moved to] they stated that I was not entitled to any support and cut my care package from 30 hours to four hours a week without asking. This has meant that I have had to make a series of complaints and now the department are scared of me and treat me like a god!"

A student who was not moving home had to make 26 complaints about the assessment: *"It has now been resolved and they have thrown more hours at me".*

Some suggested that disabled students should be encouraged to get involved in the disability movement, because they said that if disabled people realise that they are politically oppressed they can begin to change things for themselves. Often, they claimed, a lot of disabled people are influenced in their views of themselves by families with an oppressive view of disability.

Challenge is tough but gets results

Students who were assertive and able to challenge decisions often ended up with a superior service. One interviewee told us that she had a very good care package because there was a very strong organisation of disabled people in her borough. The department responsible for assessments had to offer a decent service or they would be challenged.

The fact that there is no consistent assessment procedure makes the need to be assertive all the more imperative. One interviewee said it had taken her 15 years to learn this lesson and get an adequate care package:

"About 15 years ago I only received support from one person three times a day and this would really limit me in what I could do and when I could do it. Now however, I am on a 24-hour care package as I recently complained to the local authority and they gave me more hours."

However, this kind of challenge requires a lot of confidence and can be very hard to maintain because of what was described as "a constant battering down". Many students felt that there needed to be more disabled people speaking out and that funding bodies have a duty to take account of disabled people's views.

When students felt they had been treated unfairly they had to fight to get a package would actually meet all their requirements. This was made all

the harder because there are no hard and fast rules about what should be provided.

One student, for example, was only funded for 21 hours care a week, or three hours a day. Without help it takes her over two hours in the morning to get ready for college and she is late for lectures. To increase the level of care she had to negotiate between three bodies: the access centre of the university, her local education authority and her social services department. Eventually she was offered funding to cover a PA for 12 hours a day and someone on a night-time retainer (paid to be available should the need arise).

Rights denied

Many students believed that because the care system is too bureaucratic and underfunded it makes some disabled people decide that it may be easier to stay at home with their families. They can avoid having to tackle the bureaucracy of the various reluctant authorities.

Students who have managed to challenge inadequate assessments and get the care package they need have the advantage of being able to live independently and enjoy more equality and opportunity to fulfil their aspirations. One of our interviewees now has the means to employ people to work for him whenever he needs and this is a huge advantage. Most interviewees told us that relying on family and friends did not allow them the independence that they wanted.

One interviewee in Scotland said having a family member as a PA affected his ability to take part in social life

"... the ILF employ my mum to help at home and this does not have an impact on me during the day at university. However, it does impact on me on a Thursday night if I want to stay out later as I need to let my mum know."

He stated that their relationship could be strained sometimes due to the mother and son relationship, but that he would feel *“rotten about sacking my mum to get someone in”*. He did appreciate that:

“there will be a time when I will have get another support worker aside from my mum or a time when my mum will no longer want to support me”.

This demonstrates an important point. University is traditionally a time where students are able to move away from home and gain independence from their families; disabled people who are using family members as carers do not get the chance to break these ties and strike out on their own.

Some felt that whether their help came from families or from the authorities they experienced discrimination, as in both cases they were compelled to appeal for help in order to obtain services that should be a matter of right. If they (and their family) were assertive and challenged decisions then the outcome was often more money. Not all interviewees had the energy or capacity to do this and most people stressed that challenging decisions was time-consuming and distracting from studies.

The personalisation agenda and direct payments should mean that disabled students will be in a better position to get their rights acknowledged. However, care needs to be taken that services are allocated on the basis of need and that budgets do not dictate the level of service, putting the onus on the disabled person to fight for an adequate care package. If students are unhappy with assessments there should be a clear appeals procedure.

7 Effect on students' university experience

This chapter focuses on students' experiences of the impact of care packages on the academic and the social side of their lives at university. They had two main concerns: the bureaucracy involved in arranging a care package and inaccessible buildings.

The interviews identified four important areas: academic studies, difficulties travelling to university from home, barriers to socialising and students' own well-being.

Many interviewees found it was so difficult and time-consuming dealing with all the different organisations that they spent more time sorting out their personal care packages at university than they did studying or making friends.

The use of personal assistants affected both academic and social lives due to the quantity of forms, number of different bodies they had to deal with and, if they were employing personal assistants directly, administering issues such as tax and national insurance. One said the only chance she had to speak to other students was in seminars and so she only ever discussed the course and the work with them.

Academic studies

The problems began right from the beginning of university:

"It is a constant worry with my care package and so this affects my academic studies. The time I could spend reading and going to classes is impeded by having to keep badgering people. I am always on the phone or the computer to someone to sort out my support."

Inaccessible buildings and barriers to social life

Like other students, people wanted to live in halls to make friends, join societies and be part of student life. Non-disabled peers often socialised in places that were not accessible to disabled students. In halls disabled students had to be on the ground floor for access and were left out when others were gathering on the upper floors. One ended up constantly sitting alone in her room. The barriers to socialising and integrating led to her leaving her residential hall after only four weeks, returning home and commuting to university.

Most people had found that only when they demonstrated the need for a very high level of personal care would social services ask them about their social lives and aspirations and any support that might be required in that area. Some felt that the social workers they had encountered were not willing to address all the aspects of university life. An interviewee in Scotland showed how this restricted his social life:

"If I want to go to the union in the evening then I cannot get the support. I am only entitled to care on specific hours during the week. I need to justify every one of these hours that I use and show they are based around my daily life. In total I have 40 hours a week in my care package, not including the hours I use at university"

In contrast some had care packages with 24 hours a day (or more if they required double staffing) support and – depending on building accessibility – this meant that they could go to social events.

The students we spoke to said they would like the NUS Disabled Students' Campaign to campaign to ensure that care packages take into account students' need to be able to socialise and *"go to the pub after the lecture has finished"*.

Difficulties travelling to university from home

Some people who lived at home reported problems with travelling to and from university. The student – see above – who gave up her hall of residence then had to deal with a taxi company, funded by the local education authority, whom she described as “rubbish” and suspected were used because they were comparatively cheap. The driver had no idea how to strap in wheelchairs safely which made the journey to university very frightening. Eventually, after many bitter complaints, the local education authority funded the taxi firm she had used at sixth form, who were trained and equipped for disabled passengers.

Students’ well-being

Some interviewees who did not receive enough hours of support or who had it provided by low-quality agency staff described its effect on their feelings of well-being: their general physical health deteriorated.

One developed frequent infections due the lack of skill and training of the staff. His overall health is now poor and the strain on friends who attempted to make up for his lack of care has driven them away. He is now too depressed to do anything about his situation.

Whether students were passive or assertive, they all had to deal in some way with either inadequate care packages or the general admin and bureaucracy. This was not good for anybody’s health and sense of well-being.

Interviewees’ need for a care package affected their overall student experience. They spent so much time sorting out PAs and access that it interfered with their studies and they were unable to socialise with their peers. University facilities are not very accessible (see page 32).

An adequate care package is essential to these students’ success at university. When individual budgets are introduced it is essential that the

bureaucracy is minimised and is sensitive to personal needs. Interviewees mainly viewed direct payments as empowering and any changes should therefore be centred around making all disabled students aware of such budgets and offering the training that they may require to operate them.

The overall effect on students' well-being is only touched on in this research. It does, however, raise serious points regarding the effects of negative experiences on disabled students and more research is needed to assess these and protect future disabled students.

8. Conclusion

Life, not numbers is about the experiences of disabled students in higher education who use personal assistants. The NUS Disabled Students' Campaign believes all disabled students using the personal care support should be able to enjoy university life to their full potential. However, from the interviews we conducted with disabled students, it is clear that there are still multiple barriers to be overcome before this aim can become a reality.

The current system of assessment allocates personal care support on the basis of how many times a day a specific type of support is needed, and from there a calculation is made as to how many hours a disabled person requires personal care. However, real lives do not break down easily into allotted times when assistance is or isn't required.

Our report highlights the urgent need for an improvement in the provision of personal care to disabled students. Recommendations include:

- an advocacy service – to work alongside students who require personal care enabling them to get the most from the services available;
- portable care packages (transferable between local authorities without loss of support);
- clearer and more widely available advice, information and guidance about care packages;
- further personalisation in the provision of care packages – giving disabled students more choice and control over the services they receive.

The new government, while stating that it supports the personalisation agenda and the increased use of direct payments, has emphasised the need to cut public spending in all areas; as a result it has shelved the Personal Care at Home Act 2010 (which included an allowance for care packages to be made portable), has established a commission into the funding of long-term care and is reviewing its position in relation to current human rights legislation. This makes it imperative that the evidence of our report highlights the negative impact that these steps will have on disabled students with personal care packages. They are already having their rights to independence, equality of education and freedom of movement under human rights legislation undermined.

The NUS Disabled Students' Campaign believes all people should have the right to pursue education to their full potential. The lack of portability inherent in the current system of care packages prevents students from moving freely to achieve this potential and therefore is breaching their basic human rights.

Once this report is published NUS will provide full support to disabled students as they devise a campaign. Disabled students need to be empowered to speak out about the barriers they face and funding bodies have a duty to involve them in decisions about their care. There is a need to challenge the power relationship between those receiving the services and those who shape and deliver them.

The NUS Disabled Students' Campaign's is committed to ensuring disabled students have a more positive experience in higher education. We are calling on the NUS Disabled Students' Campaign, students unions, local authorities, government and higher education institutions to respond to the report's recommendations.

Appendix A

How the report was produced

Participants

Thirteen disabled people who use personal care assistants were recruited via an advertisement on NUS website. Two of the interviewees were members of the NUS Disabled Students' Campaign.

Finding and recruiting participants was a challenge. One participant, due to the nature of his disability, could not be interviewed by the researcher but he agreed to share his experiences with a member of the NUS Disabled Students' Committee with whom he was already acquainted.

With the exception of one interviewee, all individuals were, at the time of interview, higher education students. The person who was not studying had previously attended three different higher education establishments and therefore could offer information on the uniformity of provision.

The researcher would have liked to set up focus groups in regions, but due to the relatively low numbers of students using personal care packages this was not possible. Students were interviewed individually. Interviews were held at eight universities, only two of the participants attended the same institution, two further interviews took place at NUS offices, two in participants' homes and two were conducted via email.

A semi-structured interview – see Appendix B – explored experiences of using personal care and of the barriers this created to going to university, integrating upon starting university and living independently. The aim was to allow each individual the opportunity to discuss issues, challenges and stresses they encountered as students and to identify ways in which systems can be improved to allow personal care users at university a higher quality of experience.

The first interviewees were members of the NUS Disabled Students' Committee. A further 12 interviews corroborated and strengthened the initial findings. The researcher noted that similar information was being repeated in each interviewee and felt that data saturation had clearly been reached and it was unlikely that further research would provide any additional material.³⁶

The interviews were held in Bournemouth, Bath, Canterbury, London, Cambridge, Manchester, Staffordshire and Scotland; participants consistently identified similar experiences.

Reliability of the analysis

All participants, except two who communicated by email, were interviewed verbally using a sign language interpreter and a notetaker. The interviews were transcribed in such a way as to maintain anonymity. After reviewing data, discussion on identified themes took place and text passages were inserted alongside the relevant themes. The aim was to highlight the challenges faced by disabled students using personal care provision at university.

Results

Following agreement on the identified themes, sub-themes that disabled students faced were grouped under seven main themes:

- disabled students' choice of university/course
- starting at university
- students attending university in their home area
- students having to renegotiate care packages
- support provided by universities
- assessment procedures by social services
- service from care agencies
- students' varying abilities to fight for adequate services

³⁶ Mason, J. (1996). *Qualitative researching*. Thousand Oaks, USA: Sage Publications.

- effect on students' overall university experience

During interviews, despite coming from a variety of backgrounds, all students related experiences of discrimination and incompetence with regard to the administration of their care packages.

Appendix B

Interview transcript

Disabled students' use of personal assistant (PA) and funding of PA

Use of PA

- Please describe your PA service.
- In what situations and for how many hours do you have support from a PA (ie, academic, personal and social life)?
- How is this funded?
- Has using a PA has affected any aspects of your academic life (ie, choice of university or course, ability to complete your course, social life, everyday life)

Shortcomings in service

- Is the support you receive adequate?
- Do you have to rely on your family/friends? Why?
- What happens if they cannot help you, what is your next move for help?

Advice

- Did you go straight to university after leaving school or further education college?
- If yes what advice did the SENCO or additional learning needs manager give to you about transition?
- Did they provide advice about your academic and personal care requirements?
- Was this advice adequate?

Assessment process and funding

- Did you approach social services for support?
- What did you think about the assessment process?
- Were you able to challenge any unhelpful attitudes? How?

- Did you approach the university for support?
- What did you think about the assessment process?
- Were you able to challenge any unhelpful attitudes? How?
- (If not already discussed – the system over the last three years has changed from rigid numbers to looking at the individual's needs – has this change of emphasis affected your care package)
- Was it clear who was responsible for funding your PA provision?
- Do you receive DSA to pay for support?
- Does it include PA's expenses?
- Do you have funding to receive PA support at university for non-academic situations (ie, breaks, social life)? How is it funded?
- Were you satisfied with the outcome(s) of your assessment(s)? Why?

Achieving a satisfactory care package and portability

- Have you had to develop your own confidence and ability to challenge the authorities in order to get the care package you need?
- Have you had to change your care package at any time?
- If yes, how easy was this?
- Do you feel able to move areas/universities if you want?
- What would the effect be on your care package?

Improvements

- How could the process be improved?
- What changes would be necessary to improve equality between disabled and non-disabled students'?
- What changes do you want the Government to make? (ie, advisory groups, clear guidelines for funding bodies)
- Is there anything you would like the NUS to do? (ie, advocacy service, campaign for access to all areas, stress the importance decisions based on individual need rather than budget, research)

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If you need this document in another format,
please contact kathleen.grehan@nus.org.uk
The full report can be downloaded from the NUS
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National Union of Students

4th Floor, 184–192 Drummond Street,
London NW1 3HP

t. 020 7380 6600

f. 020 7380 6627

w. www.nus.org.uk



national union of students