



NORTHERN
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The Human Rights of Carers

in Northern Ireland



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Foreword

There are now at least 214,000 carers in Northern Ireland providing unpaid care through looking after frail, ill or disabled family members, partners or friends. Research from the University of Leeds in 2011 put the economic value of unpaid care in Northern Ireland at £4.4 billion pounds. One in five carers give up work to care while many others have to adjust their working hours to meet caring responsibilities. As a result, carers suffer a loss in income. The impact, however, is not just economic in that carers are more likely to suffer ill-health than those who do not have to provide care. Moreover, children who are carers do worse at school than their classmates who do not have such responsibilities.

Caring can be rewarding and fulfilling as well as demanding. What is important for many carers is the need for recognition of the role being played and that support should be available and easy to access. Too often obtaining support can simply be a further additional struggle to be overcome.

Carers are not a homogenous group. Carers can be all ages from children to the very elderly who are looking after family members. Each carer is an individual who has her or his own story to tell and particular needs. It is why the right to an individual carer's assessment needs to be fully realised.

A number of human rights instruments can potentially impact on the role of caring from the right to an adequate standard of living and social security through to the right to meaningful participation and involvement when decisions are being taken which affect carers and the people being looked after.

This research paper is designed to offer a practical approach by setting out the main human rights laws alongside key domestic legislative and policy provision. It also covers the findings from a number of focus groups of carers convened by Carers NI. A number of specific recommendations are made which are designed to improve the support available to carers.

A rights based framework is needed to ensure public services, and policies are developed which properly recognise, identify and support carers. We hope that this publication will move us towards meeting that goal.

Les Allamby
Chief Commissioner

Executive summary: recommendations

In this report the Northern Ireland Human Rights Commission (NIHRC) analyses relevant laws, policies, and practices and their effectiveness in protecting and promoting the human rights of carers of adults. Carers NI has assisted the NIHRC in this research.

The NIHRC has collated the human rights standards relevant to the identified needs of carers. An analysis was completed to measure the recorded experiences of carers set against the obligations of the NI Executive and other relevant public authorities. The report also considers the potential implications of proposed government reforms. It concludes by making a series of recommendations directed towards ensuring an increased level of compliance as summarised below.

1. NIHRC recommends that the Department of Health, Social Services and Public Safety (DHSSPS) give specific consideration to the concerns and needs of older carers. In particular, raising greater awareness among older carers of the available mechanisms of support should be a priority.
2. The preamble to the United Nations Convention on the Rights of the Child (UNCRC) recognises that “for the full and harmonious development of his or her personality, [a child] should grow up in a family environment”. The NIHRC recommends that the DHSSPS and the Office of the First Minister and deputy First Minister (OFMdFM) should assess the level of support currently given to families where a child is involved in a caring role.
3. Noting the additional financial burdens that families with a disabled member and carers may face, the NIHRC recommends that NI Executive programmes aimed at alleviating poverty, including fuel poverty, must take full account of the challenges faced by carers. This matter should be considered by the OFMdFM.
4. The NIHRC recommends that the Department for Social Development (DSD) intensify efforts to ensure a greater uptake of social security benefits amongst carers.
5. Noting that costs associated with the provision of caring may be significant, the NIHRC recommends that the DSD evaluate whether the Carer’s Allowance adequately compensates carers for the cost of caring in all circumstances.
6. The NIHRC recommends that the potential impact of welfare reform proposals must be analysed by the DSD to ensure the proposals do not adversely impact on the ability of families currently in receipt of Disability Living Allowance (DLA) and Carer’s Allowance to enjoy an adequate standard of living. This should entail examining whether a fund to ameliorate the impact of these changes for people adversely affected and their carers should be introduced. In circumstances where there are significant costs arising from a person’s disability and in the provision of care, the potential for families to encounter difficulties in affording heating and food must be considered.
7. Noting the obligation to adopt legislation or to take other measures to ensure equal access to work for carers, the NIHRC recommends that the NI Executive, and in particular the Department for Employment and Learning (DEL), consider taking steps to enhance legal protections for carers seeking to exercise the right to work. In addition DEL should work with employers and carers organisations to develop resources for exit interviews for carers leaving work so that individuals can be signposted to advice and support. This should also be available to people of working age whose caring responsibilities have recently come to an end.

8. Noting the reality that child carers encounter difficulties in obtaining qualifications and employability skills, the NIHRC recommends that the DEL prioritise support for child and young carers in relevant educational initiatives. The Department of Finance and Personnel should consider how procurement policies can be used to encourage support for carers to be further embedded in the workplace.
9. The Department of Education should create a statutory duty on educational bodies to support young and student carers.¹ Noting concerns regarding educational achievement amongst carers, the NIHRC recommends that further research be carried out into this matter. Such research should consider the application of the Carer's Assessment and Children (NI) Order to determine if both mechanisms are sufficiently robust.
10. The NIHRC recommends that current mechanisms for the recording of the number of carers in HSC Trusts be reviewed to ensure that they are sufficiently robust and consistent across the jurisdiction. The DHSSPS should also place greater emphasis on the collection of information on the health and wellbeing of carers to enable early interventions.
11. Noting the important role played by the carer's assessment in the fulfilment of the NI Executive's human rights obligations towards carers, the NIHRC recommends:
 - a that the DHSSPS assess how effectively Health and Social Care (HSC) Trusts are meeting their duty to ensure all carers are made fully aware of their right to seek a carer's assessment;
 - b that human rights considerations be fully integrated within the process for determining what supports are to be provided to carers by HSC Trusts. In particular, decision makers should be required to consider obstacles to carers fully enjoying the right to health, the right to education, the right to work and the right to maintain an adequate standard of health and well being;
 - c where an obstacle to full enjoyment of a right is identified the decision maker should be required to demonstrate what supports have been put in place to address this;
 - d greater provision should be made by HSC Trusts for reviewing the effectiveness of supports put in place;
 - e a carer's assessment should specifically consider whether the carer requires preventative treatments;
 - f specific consideration should be given to the rights of children aged 16 or 17 who undergo a carer's assessment;
 - g DSD and DHSSPS should develop arrangements so that any successful claim for Carer's Allowance can lead to the claimant being given advice and support to apply for a carer's assessment where one is not already in place.
12. Considering the impact which caring responsibilities will have on a child, specific provision is required to ensure that the NI Executive is fulfilling its human rights obligation towards child carers. The NIHRC recommends that the DHSSPS introduce a child carer assessment similar to that operating in England and Wales.

¹ See Education (Additional Support for Learning) (Scotland) Act in 2004, as amended

13. The NIHRC has found that the right of the carer and the cared for person to participate is not fully considered when decisions are taken regarding support for the cared for person. The NIHRC notes that enhanced participation of cared for persons can lead to positive outcomes for both the carer and cared for person. The NIHRC recommends that the DHSSPS review the current processes to ensure that enhanced provision for direct payments in the health and social care system are accompanied by increased participation in decision making. Further, the DHSSPS should assess the level of support and advice provided to those who are managing direct payments.
14. The NIHRC recommends that the DHSSPS consider introducing a duty on the HSC Trusts to identify the extent to which child carers have needs for support. Assessment mechanisms should ensure adequate participation of the child in decision making processes.
15. Noting the reported lack of clarity on the inclusion of carers in the section 75 protected categories the NIHRC recommends that the OFMdfM engage with the Equality Commission NI (ECNI) and that consideration be given to issuing guidance to all NI Executive departments to ensure that the rights of carers are appropriately considered.

Overview

Scope

The NIHRC was established following the Belfast (Good Friday) Agreement, in accordance with the relevant provisions of the Northern Ireland Act 1998. It is a National Human Rights Institution with 'A status' accreditation from the International Coordinating Committee of National Institutions for the Promotion and Protection of Human Rights. The NIHRC operates in full conformity with the United Nations (UN) Principles relating to the Status of National Institutions (The Paris Principles).²

Pursuant to Sections 69(1) and (6) of the Northern Ireland Act 1998 the NIHRC reviews the adequacy and effectiveness of law and practice relating to the protection of human rights, and may undertake, commission or provide financial or other assistance for the purpose of research.

The work of the NIHRC is premised upon the full range of internationally accepted human rights standards, including the European Convention on Human Rights (ECHR) as incorporated by the Human Rights Act 1998 (HRA) and the treaty obligations of the Council of Europe and UN systems.

The Northern Ireland (NI) Executive is subject to the obligations contained within these international treaties by virtue of the UK's ratification. Section 24 (1) of the Northern Ireland Act 1998 states that *"A Minister or Northern Ireland department has no power to make, confirm or approve any subordinate legislation, or to do any act, so far as the legislation or act – (a) is incompatible with any of the Convention rights"*.

In addition, Section 26 (1) of the Northern Ireland Act 1998 provides that *"If the Secretary of State considers that any action proposed to be taken by a Minister or Northern Ireland department would be incompatible with any international obligations... he may by order direct that the proposed action shall not be taken"*.

Supplementing the treaties, there is a body of 'soft law' developed by the institutions of the UN and Council of Europe. These declarations and principles are non-binding but provide further guidance in respect of specific areas.

The following report records the experiences of carers, identifying how taking on their caring role engages and has an impact upon their human rights. It considers what steps the NI Executive and other relevant public authorities have taken to respect, protect and fulfil the rights of carers. In making an assessment, the NIHRC has taken account of domestic law, policies and practices. Where appropriate, consideration has also been given to the findings of international monitoring bodies and case law, as well as the General Comments and other interpretative texts adopted by such bodies.

Methodology

Discussions with groups of carers facilitated by Carers NI have informed the content of this report. The groups assisted in identifying the needs of carers of adults and the challenges they face. A series of semi-

² UN General Assembly Resolution 'National institutions for the promotion and protection of human rights', UN Doc. A/RES/48/134 (4 March 1994).

structured interviews were also conducted with public officials involved in the design and delivery of services to carers.

The NIHRC analysed relevant laws, policies, and practices and their effectiveness in protecting and promoting the human rights of carers of adults. Carers NI has also assisted the NIHRC by compiling and providing information, for the purposes of comparison, on initiatives developed and implemented in other jurisdictions.

The NIHRC has collated the human rights standards relevant to the identified needs of carers. An analysis was completed to measure the recorded experiences of carers set against the obligations of the NI Executive and other relevant public authorities. The report also considers the potential implications of proposed government reforms. It concludes by making a series of recommendations directed towards ensuring an increased level of compliance.

Outline of report

For the purpose of this report a carer refers to someone who provides a substantial amount of care on a regular basis to another person. This working definition is based on the content of the Carers and Direct Payments Act (NI) 2002, Section 10. The NIHRC notes that the current legislative definition only applies to those over the age of 16, however for the purpose of this report the term 'carer' includes children under the age of 16 with relevant responsibilities.

The remainder of this report proceeds as follows. Chapter 1. provides detail on the human rights law of relevance to the experience of carers. Chapter 2. details relevant statistics, domestic laws and policies. Chapter 3 sets out the proposed reforms to laws and policies of relevance to carers. Chapter 4 recounts the experiences of carers and analyses laws, policies and practices set against human rights standards, drawing conclusions and making a series of recommendations for action.

International human rights law

Introduction

International human rights law does not systematically address the issue of unpaid care work.³ The experiences of carers may however engage a number of human rights standards, the most relevant of which include:

- the European Convention on Human Rights, 1950 (ECHR) [UK ratification 1951];
- the International Labour Organisation Social Security (Minimum Standards) Convention, 1952 (ILO Minimum Standards) [UK ratification 1954];
- the European Social Charter, 1961 [UK ratification 1962];
- European Code of Social Security, 1964 [UK ratification 1968];
- the International Covenant on Civil and Political Rights, 1966 (ICCPR) [UK ratification 1976];
- the International Convention on the Elimination of all Forms of Racial Discrimination, 1966 (ICERD) [UK ratification 1969];
- the International Covenant on Economic, Social and Cultural Rights, 1966 (ICESCR) [UK ratification 1976];
- the Convention on the Elimination of all Forms of Discrimination Against Women, 1979 (CEDAW) [UK ratification 1986];
- the Convention on the Rights of Persons with Disabilities, 2006 (UNCRPD) [UK ratification 2009]; and,
- the Convention on the Rights of the Child (UNCRC) [UK ratification 1991].

In addition to these treaties there exists a body of 'soft law' developed by the human rights bodies of the United Nations and the Council of Europe. These declarations, principles and resolutions are non-binding but provide further guidance in respect of specific areas that are relevant to the human rights of carers.

The Vienna International Plan of Action on Ageing at Recommendation 26, states:

Appropriate support from the wider community, available when and where it is needed, can make a crucial difference to the willingness and ability of families to continue to care for elderly relatives. Planning and provision of services should take full account of the needs of those carers.

The Madrid International Plan of Action on Ageing (2002) recommends that States: *"Develop programmes to support self-help and provide respite care for patients, families and other carers"*.⁴

The Council of Europe Action Plan to Promote the Rights of People with Disabilities (2006) recommends that States: *"recognise the status of carers, by providing them with support and relevant training"*.⁵

³ Observer Paper submitted by Magdalena Sepúlveda Carmona* 'United Nations Special Rapporteur on extreme poverty and human rights UN Women 'Unpaid care work, poverty and women's human rights: challenges and opportunities for the post-2015 agenda' EGM/MDG/OP.1 October 2013

⁴ Developed at the Second World Assembly on Ageing 2002 held in Madrid, Spain 8-12 April 2002

⁵ Recommendation Rec(2006)5 – Adopted by the Committee of Ministers on 5 April 2006 at the 961st meeting of the Ministers' Deputies

The Committee of Ministers Recommendation on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society (2009) requires that:

Regular periods of respite care should be available to provide family carers with a break from their responsibilities. This helps to ensure that home-based supported living can continue for as long as possible.⁶

The principal emphasis within many human rights standards is on the provision of support for carers to enable them to carry out their caring responsibilities towards an ageing person or a person with a disability. International human rights treaty bodies have not systematically addressed the issue of unpaid care work.⁷

Caring, and its impact on both those who carry out the role and those who receive care, engages both civil and political rights and socio-economic rights. The provision of socio-economic rights in particular, requires positive actions by the State and investment of public resources. States are required to *“take steps to the maximum of their available resources to achieve progressively the full realisation of economic, social and cultural rights”*.⁸

The full realisation of State obligations requires actions that respect, protect and fulfil human rights. In summary:

[t]he obligation to respect means that States must refrain from interfering with or curtailing the enjoyment of human rights. The obligation to protect requires States to protect individuals and groups against human rights abuses. The obligation to fulfil means that States must take positive action to facilitate the enjoyment of basic human rights.⁹

The right to family life

The right to family life is protected by the ICCPR, Article 23, the CRC, Article 16 and the ECHR, Article 8.

The ECHR, Article 8 states:

1. **Everyone has the right to respect for his private and family life, his home and his correspondence.**
2. **There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.**

Article 8 involves rights which are central to an individual’s *“identity, self-determination, physical and moral integrity, maintenance of relationships with others and a settled and secure place in the community”*.¹⁰

⁶ Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (Adopted by the Committee of Ministers on 5 April 2006 at the 961st meeting of the Ministers’ Deputies)

⁷ Ibid., footnote 2

⁸ Office of the High Commissioner for Human Rights, ‘Factsheet No 33: Frequently Asked Questions on Economic, Social and Cultural Rights’, December 2008, at 11.

⁹ Available at <http://www.ohchr.org/EN/AboutUs/Pages/FrequentlyAskedQuestions.aspx> (Last visited 21 January 2014).

¹⁰ *Connors v UK* (Application no. 66746/01) 27 May 2004 para 82

Due to the level of commitment required of informal carers their ability to develop relationships with the outside world is often limited.¹¹ In circumstances where a child has been separated from his/her parents, the state is under a positive obligation to preserve family life so far as possible.¹² This obligation may be relevant where a parent has a disability and is reliant upon a child for care.

In the case of *Bernard*, the High Court of England and Wales found that a consistent failure by a local council to provide appropriate accommodation to a disabled woman, her husband and six children:

showed a singular lack of respect for the claimants' private and family life. It condemned the claimants to living conditions which made it virtually impossible for them to have any meaningful private or family life for the purposes of Article 8.¹³

In a second domestic case of *R (A and B) v East Sussex County Council*¹⁴ the Court of Appeal in England and Wales recognised the importance of dignity both as a human rights concept and as a fundamental value:

True it is that the phrase [human dignity] is not used in the Convention but it is surely immanent in Article 8, indeed in almost every one of the Convention's provisions. The recognition and protection of human dignity is one of the core values - in truth, the core value - of our society [...].¹⁵

This case related to the rights of care workers employed by East Sussex County Council, the cared for person and her husband who also acted as her informal carer. In the judgement the Court acknowledged the need to ensure a 'fair balance' is struck between the rights of all parties.¹⁶ The judgement therefore recognised the need to acknowledge the rights of informal carers.

The right to an adequate standard of living

Taking on a caring role can impact on the standard of living enjoyed by an individual due to costs incurred by carers and due to the impact on the ability of a carer to obtain employment. Taking on a caring role can impact on the standard of living enjoyed by an individual due to costs incurred by carers and due to the impact on the ability of a carer to obtain employment.

The right to an adequate standard of living is protected by the ICESCR, Article 11. Para 1 affirms:

The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co-operation based on free consent.

¹¹ *Niemetz v. Germany*

¹² *K. and T. v. Finland*

¹³ *R (Bernard) v Enfield London Borough Council*. (2003) LGR 423

¹⁴ [2003] EWHC 167 (Admin)

¹⁵ *Ibid.*, Para 116-18

¹⁶ *Ibid.*, Para 129

The ICESCR Committee has elaborated that the State must ensure:

The availability of food in a quantity and quality sufficient to satisfy the dietary needs of individuals, free from adverse substances, and acceptable within a given culture.¹⁷

Furthermore, the State must also ensure:

Personal or household financial costs associated with housing should be at such a level that the attainment and satisfaction of other basic needs are not threatened or compromised. Steps should be taken by States parties to ensure that the percentage of housing-related costs is, in general, commensurate with income levels.¹⁸

The CRC, Article 27 affirms that:

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.
2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development
3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing."

The right to social security

The right to social security is protected by the ICESCR, Article 9, which requires:

The State Parties to the present Covenant recognize the right of everyone to social security, including social insurance.

As previously noted, due to the financial implications of caring, informal carers may require support to maintain an adequate standard of living. In circumstances where any individual has inadequate resources to maintain an adequate standard of living the State is under an obligation to provide benefits by way of a social security system.

General Comment 6 of the ICESCR Committee elaborates that:

the term "social security" implicitly covers all the risks involved in the loss of means of subsistence for reasons beyond a person's control.¹⁹

The Committee has also identified nine principal branches of social security. This includes a recognition that:

Benefits for families are crucial for realizing the rights of children and adult dependents to protection under Articles 9 and 10 of the Covenant. In providing the benefits, the State party

¹⁷ General comment No. 12: The right to adequate food (art. 11) E/C.12/1999/5. Para 8

¹⁸ General comment No. 4: The right to adequate housing (art. 11 (1) of the Covenant) para 8 (b)

¹⁹ General comment No. 6: The economic, social and cultural rights of older persons E/1996/22

should take into account the resources and circumstances of the child and persons having responsibility for the maintenance of the child or adult dependent, as well as any other consideration relevant to an application for benefits made by or on behalf of the child or adult dependent. Family and child benefits, including cash benefits and social services, should be provided to families, without discrimination on prohibited grounds, and would ordinarily cover food, clothing, housing, water and sanitation, or other rights as appropriate.²⁰

In addition, to insurance schemes:

Other forms of social security are also acceptable, including (a) privately run schemes, and (b) self-help or other measures, such as community-based or mutual schemes. Whichever system is chosen, it must conform to the essential elements of the right to social security and to that extent should be viewed as contributing to the right to social security and be protected by States parties in accordance with this general comment.²¹

The ICESCR Committee has clarified that Article 9 “*implicitly recognizes the right to old-age benefits*”.²²

In its General Comment on social security, the Committee cross-referenced to the General Comment on persons with disabilities and recognised specific responsibilities towards carers. The Committee stated:

In its general comment No. 5 (1994) on persons with disabilities, the Committee emphasized the importance of providing adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost, or received a reduction in, their income, have been denied employment opportunities or have a permanent disability. Such support should be provided in a dignified manner and reflect the special needs for assistance and other expenses often associated with disability. The support provided should cover family members and other informal carers.²³

²⁰ Committee on Economic, Social and Cultural Rights, General Comment 19, The right to social security (art. 9) (Thirty-ninth session, 2007), U.N. Doc. E/C.12/GC/19 (2008). para 18

²¹ General comment No. 19:1 The right to social security (art. 9) para 5

²² Ibid.

²³ Committee on Economic, Social and Cultural Rights, General Comment 19, The right to social security (art. 9) (Thirty-ninth session, 2007), U.N. Doc. E/C.12/GC/19 (2008). Para 20

The European Social Charter, Article 13 also protects the right to social security declaring:

With a view to ensuring the effective exercise of the right to social security, the Contracting Parties undertake:

1. to establish or maintain a system of social security;
2. to maintain the social security system at a satisfactory level at least equal to that required for ratification of International Labour Convention No. 102 Concerning Minimum Standards of Social Security;
3. to endeavour to raise progressively the system of social security to a higher level;
4. to take steps, by the conclusion of appropriate bilateral and multilateral agreements, or by other means, and subject to the conditions laid down in such agreements, in order to ensure:
 - a. equal treatment with their own nationals of the nationals of other Contracting Parties in respect of social security rights, including the retention of benefits arising out of social security legislation, whatever movements the persons protected may undertake between the territories of the Contracting Parties;
 - b. the granting, maintenance and resumption of social security rights by such means as the accumulation of insurance or employment periods completed under the legislation of each of the Contracting Parties.

The Charter elaborates on these obligations at Article 12 as follows:

With a view to ensuring the effective exercise of the right to social and medical assistance, the Contracting Parties undertake:

1. to ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition;
2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want
4. to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Contracting Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11th December 1953.

The Charter addresses the issue of social welfare services at Article 14, stating that:

With a view to ensuring the effective exercise of the right to benefit from social welfare services, the Contracting Parties undertake:

1. **to promote or provide services which, by using methods of social work, would contribute to the welfare and development of both individuals and groups in the community, and to their adjustment to the social environment;**
2. **to encourage the participation of individuals and voluntary or other organisations in the establishment and maintenance of such services.**

The right to work

Informal carers may experience difficulties exercising the right to work due to the absence of alternative care provision or inflexible working arrangements within the labour market.²⁴

The ICESCR protects the right to work. Article 6 affirms that:

1. **The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.**
2. **The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.**

The ICESCR Committee has elaborated that the provision, facilitation and promotion of the right to work requires the State to “[adopt] legislation or to take other measures ensuring equal access to work and training”.²⁵

The Committee has explained that a “*failure to adopt or implement a national employment policy designed to ensure the right to work for everyone; insufficient expenditure or misallocation of public funds which results in the non-enjoyment of the right to work by individuals or groups, particularly the disadvantaged and marginalized*” may amount to a violation of the obligation to fulfil the right to work.²⁶

²⁴ See Chapter 4 discussion under right to work

²⁵ General Comment No. 18 : . 06/02/2006. E/C.12/GC/18. (General Comments: The right to work (art. 6) Para 20

²⁶ General Comment No. 18 : . 06/02/2006. E/C.12/GC/18. (General Comments: The right to work (art. 6) para 36

The European Social Charter, Article 1, also recognises the right to work, affirming:

With a view to ensuring the effective exercise of the right to work, the Contracting Parties undertake:

1. to accept as one of their primary aims and responsibilities the achievement and maintenance of as high and stable a level of employment as possible, with a view to the attainment of full employment;
2. to protect effectively the right of the worker to earn his living in an occupation freely entered upon;
3. to establish or maintain free employment services for all workers;
4. to provide or promote appropriate vocational guidance, training and rehabilitation.

The Charter further elaborates on just conditions, safe and healthy working conditions and adequate rates of remuneration.

The CRC, Article 32 states:

1. States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.
2. States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular:
 - a. Provide for a minimum age or minimum ages for admission to employment;
 - b. Provide for appropriate regulation of the hours and conditions of employment;
 - c. Provide for appropriate penalties or other sanctions to ensure the effective enforcement of the present article.

The right to education

In accordance with the ICESCR, Article 13:

1. The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.
2. The States Parties to the present Covenant recognize that, with a view to achieving the full realization of this right:
 - a. Primary education shall be compulsory and available free to all;
 - b. Secondary education in its different forms, including technical and vocational secondary education, shall be made generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education;
 - c. Higher education shall be made equally accessible to all, on the basis of capacity, by every appropriate means, and in particular by the progressive introduction of free education;
 - d. Fundamental education shall be encouraged or intensified as far as possible for those persons who have not received or completed the whole period of their primary education;
 - e. The development of a system of schools at all levels shall be actively pursued, an adequate fellowship system shall be established, and the material conditions of teaching staff shall be continuously improved."
3. The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to choose for their children schools, other than those established by the public authorities, which conform to such minimum educational standards as may be laid down or approved by the State and to ensure the religious and moral education of their children in conformity with their own convictions
4. No part of this article shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principles set forth in paragraph 1 of this article and to the requirement that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

The ICESCR Committee elaborated on the right to education stating that:

The right to education, like all human rights, imposes three types or levels of obligations on States parties: the obligations to respect, protect and fulfil. In turn, the obligation to fulfil incorporates both an obligation to facilitate and an obligation to provide....The obligation to fulfil (facilitate) requires States to take positive measures that enable and assist individuals and communities to enjoy the right to education.²⁷

The ECHR, Article 2 Protocol 1 requires that:

No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and teaching, the state shall respect the rights of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions.

With respect to children the Charter provides that those who are still subject to compulsory education shall not be employed in such work as would deprive them of the full benefit of their education.²⁸

The CRC, at Article 28 states:

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:
 - a. Make primary education compulsory and available free to all;
 - b. Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;
 - c. Make higher education accessible to all on the basis of capacity by every appropriate means;
 - d. Make educational and vocational information and guidance available and accessible to all children;
 - e. Take measures to encourage regular attendance at schools and the reduction of drop-out rates.
2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.
3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

²⁷ General comment No. 13: The right to education (art. 13) para 46 & 47

²⁸ Article 7(3)

The State has an obligation to facilitate individuals to exercise the right to education. Caring responsibilities may inhibit the ability of an informal carer to engage fully in educational opportunities. The State must ensure children in compulsory education are not employed in such work as would deprive them of the full benefit of their education. The provision of caring duties is not a form of employment but can have similar detrimental implications on the ability of a child to engage in education.

The right to health

Informal carers often encounter health problems related to their caring responsibilities, these can be mental or physical.²⁹ Furthermore the time commitment involved in caring can inhibit the ability of carers to access preventative treatments.

The ICESCR protects the right to health. Article 12 declares:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
 - a. The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
 - b. The improvement of all aspects of environmental and industrial hygiene;
 - a. The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
 - a. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

The ICESCR Committee has elaborated on the meaning of Article 12 and specified that:

the express wording of article 12.2 acknowledges that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life ...³⁰

The Committee has elaborated that under Article 12.2(d) the State must ensure *“the provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education ...”*³¹ It has further elaborated that:

“The obligation to fulfil requires States parties, inter alia, to give sufficient recognition to the right to health in the national political and legal systems, preferably by way of legislative implementation, and to adopt a national health policy with a detailed plan for realizing the right to health.... Violations of the obligation to fulfil occur through the failure of States parties to take all necessary steps to ensure the realization of the right to health. Examples include the

²⁹ See Chapter 4 right to health

³⁰ Committee on Economic, Social and Cultural Rights, General Comment 14, The right to the highest attainable standard of health (Twenty-second session, 2000), U.N. Doc. E/C.12/2000/4 (2000), reprinted in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.6 at 85 (2003). Para 17

³¹ Ibid., para 52

failure to adopt or implement a national health policy designed to ensure the right to health for everyone; insufficient expenditure or misallocation of public resources which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized...³²

The right to participation

There are many decision making processes relating to both carers and the cared for person. The extent to which decision making processes facilitate the meaningful participation of the carer or indeed the cared for person has been questioned, this is discussed in detail in chapter 4.³³

The UNCRC at Article 12 states:

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

The UN Special Rapporteur on Poverty and Human Rights has found that the right to participation is enshrined in numerous international human rights instruments.³⁴ The Special Rapporteur's 2013 report to the UN Human Rights Council sets out the key attributes of a human rights based approach. It emphasised that:

Rights-based participation is particularly necessary in order to ensure that the poorest and most marginalized people can make their voices heard, because of its principled foundations of dignity, non-discrimination and equality. Therefore, in contrast to some supposedly "participatory" processes that are pro forma, tokenistic or undertaken to give predetermined policies a veneer of legitimacy, rights-based participation aims to be transformative rather than superficial or instrumental. It promotes and requires the active, free, informed and meaningful participation of persons living in poverty at all stages of the design, implementation and evaluation of policies that affect them, based on a comprehensive analysis of their rights, capacity and vulnerabilities, power relations, gender relations and the roles of different actors and institutions.³⁵

³² Ibid., Para 36

³³ See Chapter 4

³⁴ including the Universal Declaration of Human Rights (arts. 21 and 27), the International Covenant on Civil and Political Rights (art. 25), the International Covenant on Economic, Social and Cultural Rights (arts. 13.1 and 15.1), the Convention on the Elimination of All Forms of Discrimination Against Women (arts. 7, 8, 13(c) and 14.2), the International Convention on Elimination of All Forms of Racial Discrimination (art. 5(e)(vi)), the Convention on the Rights of the Child (arts. 12 and 31), the Convention on the Rights of Persons with Disabilities (arts. 3(c), 4.3, 9, 29 and 30), the International Convention on the Rights of All Migrant Workers and Members of their Families (arts. 41 and 42.2), the United Nations Declaration on the Right to Development (arts. 1.1, 2 and 8.2) and the United Nations Declaration on the Rights of Indigenous Peoples (arts. 5, 18, 19 and 41).

³⁵ Human Rights Council Twenty-third session Agenda item 3 Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development Report of the Special Rapporteur on extreme poverty and human rights, Magdalena Sepúlveda Carmona A/HRC/23/36 11 March 2013 para 17

At all levels of government there must be:

a legal obligation to implement inclusive, meaningful and non-discriminatory participatory processes and mechanisms, and to engage constructively with the outcomes.³⁶

The rights of persons with disabilities

The UNCRPD has been developed 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.³⁷ Carers may have disabilities and with the increasing proportion of persons caring into older life it is likely that a growing proportion of carers will have acquired disabilities.

An informal carer plays an important role in ensuring that a person with a disability is able to enjoy the rights protected by the UNCRPD. The failure of the State to realise the rights of a person with a disability can have significant implications for the ability of a carer to enjoy the human rights guaranteed to them.

The right to equal recognition before the law is protected by the UNCRPD, Article 12 which states:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

³⁶ Ibid., para 14

³⁷ UNCRPD Article 1

The right to live independently, protected by the UNCRPD, Article 19, declares:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The right to personal mobility is protected by the UNCRPD, Article 20 which affirms that:

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a. Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- b. Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c. Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- d. Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

The right to an adequate standard of living and to social protection is protected by the UNCRPD, Article 28 that declares:

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
 - a. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
 - b. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes
 - c. To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care
 - d. To ensure access by persons with disabilities to public housing programmes
 - e. To ensure equal access by persons with disabilities to retirement benefits and programmes.

Children's rights

The preamble to the UNCRC states that children, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding. The NIHRC notes that in circumstances where a child is required to spend a significant amount of their time performing caring duties their development may be hampered.

A number of protected human rights within the UNCRC may be engaged to address the specific needs of children who are carers. In particular, where children are involved, Article 3 will always be engaged and must be given due weight. It states:

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

In addition the UNCRC recognises the child's right to rest and leisure. Article 31 states:

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

With respect to children the extent of caring responsibilities, in particular the time required, may restrict their ability to rest and engage in leisure activities.

Background: legislation and policy

In this chapter we set out some key statistics on the number of carers in Northern Ireland and on research that has been conducted into the challenges they face. It goes on to identify key legislation and policies relevant to carers.

Statistics

The Census 2011

The 2011 census of Northern Ireland carried out by Northern Ireland Statistics and Research Agency (NISRA) contains significant data on the numbers and circumstances of informal carers.³⁸

Census figures indicate that of a population of 1.8 million there are 213,980 informal carers in Northern Ireland. This means that 11.8% of the population provide unpaid care. The figure is proportionately higher than any other UK jurisdiction.³⁹ The total number of carers in Northern Ireland has increased by 16% since 2001. This rate of growth is more than double the rate of growth in the general population, which stood at 7.5%.

The highest proportion of carers are in the age bracket 50-64 years old. 21.3% of persons this age are carers. There are 170 people over the age of 90 providing 50 or more hours of unpaid care. This figure has almost trebled since 2001 (from 64). Of these 170 carers, 165 have a long term health problem or disability that impacts substantially on their day to day activities.

Employment figures

There are 119,455 carers in employment. This represents 56% of the total number of carers in Northern Ireland identified by the 2011 census. In terms of employed carers, 69.6% provide 1-19 hours care per week; 15.1% provide 20-49 hours care per week, and 15.3% provide 50 or more hours care per week.⁴⁰

11,106 of those who provide 50 or more hours care per week are employed for more than 30 hours per week.⁴¹ In addition 2,172 people who provide 50 or more hours of care per week also work for more than 49 hours per week.⁴²

Health

The Northern Ireland Life and Times Survey of carers was completed in 2010. Nineteen percent of respondents indicated that they felt under pressure most of the time and 40% indicated that they felt pressure sometimes.⁴³

A survey of carers of older people was also carried out by the DHSSPS in 2006. Of the respondents to this survey, 18% said that they always felt under stress because of their caring responsibilities, 21% were under stress very often and 30% were under stress quite often.⁴⁴

³⁸ The 2011 census was carried out by the Northern Ireland Statistics and Research Agency and content is available online at <http://www.nisra.gov.uk/Census.html>

³⁹ (England and Wales is 10.3%, Scotland 9%).

⁴⁰ <http://www.nisra.gov.uk/Census.html>

⁴¹ *Ibid.*

⁴² *Ibid.*

⁴³ Northern Ireland Life and Times, ARK Northern Ireland <http://www.ark.ac.uk/nilt/>. See also "An ordinary life? Caring in Northern Ireland today," Helen Ferguson and Paula Devine, ARK Research Update 75 <http://www.ark.ac.uk/publications/updates/update75.pdf> and "Who cares now? Changes in informal caring 1994 and 2006" Eileen Evason, ARK research update 51; <http://www.ark.ac.uk/publications/updates/update51.pdf>

⁴⁴ Survey of carers of older people in Northern Ireland", Community Information Branch, Department of Health, Social Services and Public Safety (DHSSPS), May 2006 <http://www.dhsspsni.gov.uk/nicarereport.pdf>

Levels of support

The results of a survey of carers of older people carried out by the DHSSPS in 2006 also indicate that:⁴⁵

- Over a quarter (26%) said that they never had breaks from caring, and over three-fifths had breaks only occasionally.
- Respondents were asked to list which things would most support them in their caring role. The most common thing mentioned was respite care or breaks for the carer.
- 43% of respondents knew that they could have a separate assessment of their needs as a carer, and 39% had been offered such an assessment.
- When asked had their health and social care trust or any other organisation asked for their opinion about services for carers in their community or area, 78% of respondents said that they had not been asked.

Questions on young carers in the Young Life and Times Survey were commissioned and published by the Patient Client Council in June 2011. The survey indicates that the provision of formal support is rare, with young carers routinely receiving help from within the family unit rather than from statutory sources.⁴⁶

Domestic law and policies

Carers and Direct Payments Act

The Carers and Direct Payments (Northern Ireland) Act 2002,⁴⁷ provides a legal definition and recognition of carers, and places duties relating to carers on public authorities.⁴⁸ In particular, it provides a right for carers to request an assessment of their ability to provide and to continue to provide care for the person cared for, this can be offered independently of whether the person they care for is having an assessment.⁴⁹

The legislation directs the relevant authority to consider whether the carer has needs in relation to the care they provide; if so, whether those needs could be met by the provision of services by the authority and if they could, whether or not to provide such services.⁵⁰ The relevant authorities are obligated to promote the availability of the carer's assessment.⁵¹

The Act also provides HSC Trusts with discretion to make Direct Payments to carers (including 16 and 17 year old carers) for the purchase of services that meet their own assessed needs.⁵² It also recognises children adversely affected by caring responsibilities as children in need under the Children (Northern Ireland) Order 1995.⁵³

⁴⁵ Ibid.

⁴⁶ Patient and Client Council *Young Carers in Northern Ireland: A report of the experiences and circumstances of 16 year old carer* June 2011 available at: http://www.patientclientcouncil.hscni.net/uploads/research/Young_carers_in_Northern_Ireland.pdf

⁴⁷ Carers and Direct Payments Act (Northern Ireland) 2002 http://www.legislation.gov.uk/nia/2002/6/pdfs/nia_20020006_en.pdf

⁴⁸ In practice this reference relates to the Health and Social Care Board and Health and Social Care Trusts.

⁴⁹ Ibid., section 1.

⁵⁰ Ibid., section 2

⁵¹ Ibid.

⁵² Ibid., sections 3 and 6

⁵³ It is the policy of the DHSSPS to treat all children who are providing care as children first and carers second. Children under 16 should have their needs assessed, and services provided, under the provisions of the Children (Northern Ireland) Order 1995.

In 2005 the DHSSPS issued a direction on the implementation of the 2002 Act entitled “Carers’ Assessment and Information Guidance” which sets out how the Act is to be implemented.⁵⁴ The Act and Guidance provide for separate assessment tools depending on the circumstances of a carer.⁵⁵

Where a carer chooses not to request a separate Carer’s Assessment, as is their right under the 2002 Act, HSC Trusts are still obliged to consider the needs and views of the carer.⁵⁶ The needs of individuals should be identified by assessment and discussed with them and their carers; and packages of appropriate care are to be assembled and agreed with individuals and carers. Even if a carer declines a separate assessment, their views still can and should be taken into account in deciding on care arrangements for the disabled or older person being supported, and this should be evidenced in care planning.

With respect to children, the Children (NI) Order 1995, Article 17A, requires an authority on request to carry out an assessment of a child carer to determine whether he/she is a “child in need” within the meaning of Article 17 of the 1995 Order. If he/she is determined to be in need, Article 18 of the 1995 Order automatically applies and will allow the authority to provide services.

A 16 or 17 year old can be assessed under the 1995 Order, or alternatively under the Carers and Direct Payments Act (Northern Ireland) 2002.

The Northern Ireland Act 1998, section 75

The Northern Ireland Act 1998 section 75 places a statutory duty on designated public bodies when carrying out their functions to have due regard to the need to promote equality of opportunity between persons with dependents and persons without.⁵⁷ Schedule 9 of the Act, and subsequent guidance from the ECNI set out how this duty is to be implemented through a process of screening and equality impact assessment.⁵⁸ It requires public bodies to consult people from each of the identified categories in policy formulation and to identify adverse impact, mitigating factors and opportunities to promote equality.⁵⁹ This means that people with dependants, including carers, should be consulted and involved in the development of policies that may affect them.

Employment legislation

The Employment Relations (Northern Ireland) Order 1999 permits carers to take leave to address emergency situations involving dependants such as a breakdown in care arrangements, illness or injury of the dependent person or the death of a dependent person.⁶⁰ It is at the employer’s discretion as to whether this leave is paid or unpaid.⁶¹

⁵⁴ Carers and Direct Payments Act (Northern Ireland) 2002: Carers’ Assessment and Information Guidance, DHSSPS, 2005 <http://www.dhsspsni.gov.uk/ec-carers-assessment-information-guidance.pdf>

⁵⁵ For adults/older people, there is a carer’s assessment section in the Northern Ireland Single Assessment Tool (NISAT); for young people it sits within UNOCINI (Understanding the Needs of Children in Northern Ireland).

⁵⁶ Section 2

⁵⁷ Northern Ireland Act 1998, Section 75 <http://www.legislation.gov.uk/ukpga/1998/47/section/75>

⁵⁸ *Ibid.*, Schedule 9 <http://www.legislation.gov.uk/ukpga/1998/47/schedule/9> and “Section 75 of the Northern Ireland Act: A Guide for Public Authorities”, Equality Commission for Northern Ireland, April 2010 <http://www.equalityni.org/archive/pdf/S75GuideforPublicAuthoritiesApril2010.pdf>

⁵⁹ *Ibid.*

⁶⁰ Employment Relations (Northern Ireland) Order 1999 <http://www.legislation.gov.uk/nisi/1999/2790/contents/made>. See Article 10 and Part II of Schedule 4 at <http://www.legislation.gov.uk/nisi/1999/2790/article/10/made> and <http://www.legislation.gov.uk/nisi/1999/2790/schedule/4/made> respectively.

⁶¹ *Ibid.*

In relation to parental leave, under the Maternity and Parental Leave Regulations (Northern Ireland) 1999 a person who is responsible for a disabled child (for whom DLA/ESA is received) is entitled to take eighteen weeks parental leave before the child's 18th birthday.⁶² The entitlement ends at the child's 18th birthday and therefore does not apply to those caring for a son or daughter over 18. There are currently proposals to allow for the sharing of parental leave entitlements.⁶³

The Work and Families (Northern Ireland) Order 2006 introduced the right to request flexible working for carers.⁶⁴ Such arrangements could include flexible start and finish times, compressed working hours, job sharing or home-working. Employers must adopt a set procedure to consider these requests, but can refuse them on certain grounds.⁶⁵ There is a right to appeal such decisions.

Health and Personal Social Services (NI) Order and subsequent guidance

The Health and Personal Social Services (Northern Ireland) Order 1972 provides the legislative framework for assessing provision of social services to persons in need.⁶⁶ The Order places a statutory duty on the relevant authorities to regularly assess and review the community care needs of all persons who appear in need of such services.⁶⁷ The Order was followed by guidance issued in the form of "People First: Community Care in Northern Ireland in the 1990s".⁶⁸ The central theme of the guidance is that services should be "*user centred and needs led*". Of particular relevance, is the recognition that the needs of individuals should be identified by assessment and discussed with them and their carers. Packages of appropriate care must be assembled based on the findings of the assessment, and through agreement with individuals and their carers. In addition, there is an acknowledgement of the need to ensure that individuals and their carers have an element of choice and the care provided should not simply reflect the availability of statutory services.

In 1991 the DHSSPS issued "People First Care Management: Guidance on Assessment and the Provision of Community Care".⁶⁹ This sets out that the authorities are required to assess the care needs of any person who appears to them to be in need of community care services and to decide, in the light of that assessment, whether they should provide, or arrange for the provision of services.⁷⁰ In relation to carers, the guidance recommends that assessments should include the needs of both the client and, where appropriate, the principal informal carer(s).

⁶² Maternity and Parental Leave Regulations (Northern Ireland) 1999 <http://www.legislation.gov.uk/nisr/1999/471/contents/made>. See Part III at <http://www.legislation.gov.uk/nisr/1999/471/part/III/made>, as amended by the Parental Leave (EU Directive) (Maternity and Parental Leave) Regulations (Northern Ireland) 2013 <http://www.legislation.gov.uk/nisr/2013/25/made>

⁶³ DEL 'Sharing Parental Rights, Extending Flexibility at Work - Public Consultation' April 2014

⁶⁴ Work and Families (Northern Ireland) Order 2006 <http://www.legislation.gov.uk/nisi/2006/1947/contents/made>. See Article 14 at <http://www.legislation.gov.uk/nisi/2006/1947/article/14/made>.

⁶⁵ Ibid.

⁶⁶ Health and Personal Social Services (Northern Ireland) Order 1972 <http://www.legislation.gov.uk/nisi/1972/1265/contents>

⁶⁷ Ibid., Article 15 <http://www.legislation.gov.uk/nisi/1972/1265/article/15>

⁶⁸ "People First: Community Care in Northern Ireland in the 1990s", DHSSPS, 1990, http://www.dhsspsni.gov.uk/people_first.pdf

⁶⁹ "People First Care Management: Guidance on Assessment and the Provision of Community Care", DHSSPS, 1991 http://www.dhsspsni.gov.uk/people_first_-_care_management_-_guidance_on_assessment_and_the_provision_of_community_care.pdf

⁷⁰ See para 2

Carers' Strategy

In 2006 the DHSSPS published "Caring for Carers". This is a regional strategy based on "*recognising, valuing and supporting the caring role*". It outlines what carers can expect from public services, particularly health and social care, in order to provide them with support.⁷¹

The strategy was developed and makes recommendations centred on six key themes: identifying and interacting with carers; information for carers; co-ordinating and involving carers in support services for carers; assessing the needs of carers; providing training for carers; supporting carers in employment and young carers.⁷²

The operation of the strategy is overseen by a regional Carers' Strategy Implementation Group. This group is co-ordinated by the Health and Social Care Board (HSCB) and comprises officials from the DHSSPS, the HSCB and HSC Trusts, the Public Health Agency, and local commissioning groups, as well as carers and a representative from Carers Northern Ireland. The group sets strategic objectives and has drafted a renewed action plan.⁷³ Its Terms of Reference specify that its purpose is to ensure the delivery of strategic priorities for the support of carers; and to do so by encouraging meaningful participation of, and partnership with, those who are carers.⁷⁴

In addition to the regional strategy, each of the Trusts has its own carers' strategy,⁷⁵ plan and implementation group.

Social security entitlements

Carer's Allowance is the main benefit for carers. A carer can access this allowance if the person they look after receives one of the following benefits:

- Attendance Allowance;
- Disability Living Allowance (at the middle/higher rate of the care component); or
- Constant Attendance Allowance.

If Personal Independence Payment is introduced then entitlement to Carer's Allowance will be linked to both rates of the daily living component.

The carers themselves must also satisfy the following conditions: they look after someone for at least 35 hours each week; are aged 16 or over; are not studying full-time; do not earn over £102 a week from work (after some deductions); and satisfy UK residence, presence and immigration rules.⁷⁶ However, if a carer is in receipt of State Retirement Pension, Incapacity Benefit, contributory Employment and Support Allowance, bereavement benefits or any other 'earnings replacement' benefit paid at or above the rate of Carer's

⁷¹ "Caring for Carers: Recognising, Valuing and Supporting the Caring Role", DHSSPS, 2006 <http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf>

⁷² Ibid.

⁷³ Ibid.

⁷⁴ See DSD/DHSSPS 'Review of the support provision for carers' September 2009 available at: <http://www.dhsspsni.gov.uk/review-of-support.pdf>

⁷⁵ See for example "Working in Partnership with Carers: A Strategy for Supporting Carers across the Western Health and Social Care Trust (2009 – 2014)" Western Health & Social Care Trust, January 2009 http://www.westerntrust.hscni.net/pdf/WHST_-_Carers_Strategy.Working_in_Partnership.final.pdf

⁷⁶ Social Security Contributions and Benefits (Northern Ireland) Act 1992 <http://www.legislation.gov.uk/ukpga/1992/7/contents>; see section 70 at <http://www.legislation.gov.uk/ukpga/1992/7/section/70> and Regulatory Reform (Carer's Allowance) Order 2002 <http://www.legislation.gov.uk/uksi/2002/1457/made>

Allowance, they are likely to be ineligible for Carer's Allowance. This is known as the overlapping benefit rule.⁷⁷

If they still meet all the criteria, then carers could have 'underlying entitlement' to Carer's Allowance, which can help them to get more financial assistance from other benefits in the form of a carer's premium. The carer's premium is an extra payment which could increase benefits such as Income Support, income-related Employment and Support Allowance, income-based Jobseeker's Allowance, and Housing Benefit. There is an equivalent amount called the carer addition which is used in Pension Credit.

Carer's Allowance is paid at a basic rate of £61.35 a week. The carer premium/addition is £34.20 a week (2014/2015 rates).⁷⁸

⁷⁷ HM Revenue & Customs EIM76007 - Social security benefits: entitlement to more than one benefit

⁷⁸ This figure is set by the Department of Works and Pensions in the UK.

Proposed reforms

There are currently a number of areas of law and policy under review which may have implications for carers. In this chapter we set out relevant reform proposals.

Transforming Your Care

In June 2011 the Minister for Health and Social Services announced a review into the provision of health and social care services in Northern Ireland. In completing its work, the review team was tasked to make recommendations on the future provision of services.⁷⁹ Published in December 2011, and known as “Transforming your Care”, the review proposed an individual-centred model of care.⁸⁰ It outlined the need to integrate services locally, provide more community-based services and care for people at home when safe and appropriate to do so.⁸¹ It envisaged a service wherein:

- Every individual will have the opportunity to make decisions that help maintain good health and wellbeing. Health and social care will provide the tools and support people need to do this;
- Most services will be provided locally, for example diagnostics, outpatients and urgent care, and local services will be better joined up with specialist hospital services;
- Services will regard home as the hub and be enabled to ensure people can be cared for at home, including at the end of life; The professionals providing health and social care services will be required to work together in a much more integrated way to plan and deliver consistently high quality care for patients;
- Where specialist hospital care is required it will be available, discharging patients into the care of local services as soon as their health and care needs permit; and,
- Some very specialist services needed by a small number of people will be provided on a planned basis in the ROI [Republic of Ireland] and other parts of the UK.

Who Cares?

A review of the provision of adult social care is currently taking place. “Who Cares?”, a pre-consultation document was published in 2013, it sets out how care is funded and where the balance of responsibility lies between the statutory, private and voluntary sectors in the provision of services. The document sought initial views on these.⁸² It also identified a number of core principles that should underpin how the future system is designed, including: dignity and respect – for everyone who uses services, their carers and the staff who provide care; equality and diversity – for everyone, regardless of circumstances, to be treated fairly and

⁷⁹ See health and social care board ‘Transforming Your Care (TYC) Engagement Feedback Report’ June 2012

⁸⁰ “Transforming Your Care: a Review of Health and Social Care in Northern Ireland”, Health and Social Care Review Team, December 2011, <http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf>

⁸¹ *Ibid.*

⁸² “Who cares? The future of Adult Care and Support in Northern Ireland”, DHSSPS, 2013 <http://www.dhsspsni.gov.uk/who-cares-future-adult-care-support-ni-discussion.pdf>

equally; and the protection and promotion of everyone's human rights – should be built into how the care and support systems work.⁸³

The published responses to this consultation highlight the importance of carers, the need not to increase the burden on them and to involve them in the design of and decisions regarding services.⁸⁴ This was the first stage in an envisaged 18 month process of remodelling care provision.

In March 2014 the then Minister for Health Mr Edwin Poots MLA made a statement to the Northern Ireland Assembly stating that the Department was:

“making significant progress in implementing those changes to transform the delivery of health and social care services to deliver the Right Care, at the Right Time, in the Right Place”.⁸⁵

The Minister went on to emphasise that:

“It is only by reshaping our model of care to provide alternative services, earlier intervention and better patient self management, that we will be able to divert that group of people to more appropriate services”.⁸⁶

Welfare Reform Bill

The full implementation of welfare reform in Northern Ireland has been delayed. The Welfare Reform Bill will bring about what are widely regarded as radical changes in the social security system⁸⁷. According to research the changes to disability benefits and the increased requirements on people with disabilities to look for work, as well as changes to Housing Benefit entitlement will impact far more on Northern Ireland than other parts of the UK⁸⁸. There are a high proportion of people with disabilities living in Northern Ireland compared to other parts of the UK due, in part, to the legacy of conflict. Just over 1 in 10 of the population in Northern Ireland is in receipt of Disability Living Allowance compared to just over 1 in 20 of the population in Great Britain⁸⁹. Over 10% of the working age population in Northern Ireland are in receipt of Incapacity Benefit (IB) or Employment Support Allowance (ESA) compared to 6.6% in Great Britain (GB).⁹⁰

⁸³ Ibid., – see principles set forth therein

⁸⁴ *“Who cares? Consultation analysis report”*, DHSSPS, August 2013 http://www.dhsspsni.gov.uk/who_cares_consultation_analysis_report.pdf

⁸⁵ Oral Statement to the Assembly by Health Minister Edwin Poots – 11 March 2014 – Progress Update on Transforming Your Care available at: <http://www.dhsspsni.gov.uk/index/statements-minister/statements-minister-2014/tycstatement110314.htm>

⁸⁶ Ibid.

⁸⁷ Northern Ireland Assembly (2011): ‘An introduction to Welfare Reform’, Research and Library Service Briefing Paper, paper 13/11, NIAR 606-10.

⁸⁸ Beatty, C. and Fothergill, S. (2013): ‘The Impact of Welfare Reform in Northern Ireland’ (Centre for Regional Economic and Social Research at Sheffield Hallam University for NI Council for Voluntary Action). Available at: http://www.nicva.org/sites/default/files/The%20Impact%20of%20Welfare%20Reform%20in%20NI_2013.pdf

⁸⁹ Department for Social Development (April 2013): ‘Welfare Reform Briefing Section 75 Update’, page 55, final paragraph, (Belfast: DSD). Available at: www.dsdni.gov.uk/welfare-reform-bill-section-75-update-april-2013.doc

⁹⁰ MacInnes, T., Aldridge, H., Parekh, A. and Kenway, P. (2012): ‘Monitoring Poverty and Social Inclusion in Northern Ireland’, (York: Joseph Rowntree Foundation).

A wide range of groups including academics, political parties, NGOs, churches, trade unions and equality and human rights bodies have expressed concerns about the potential negative impact of the reforms to social security benefits on people experiencing poverty, including disabled people.⁹¹

The proposed transition from the Disability Living Allowance⁹² (DLA) to the new Personal Independence Payment (PIP) will result in loss of income for many disabled people⁹³. It is estimated that in Northern Ireland 57% of those in receipt of DLA will either lose their entitlement completely or have their disability benefit decreased⁹⁴. Those individuals adversely affected by incapacity benefit reform are expected to lose an average of almost £3,500 per year⁹⁵. In addition as entitlement to Carer's Allowance is dependent upon the cared for person being in receipt of a qualifying disability benefit, entitlement to this benefit will also cease in some cases. Moreover this will in turn result in a reduction in additional premium payments within means tested benefits for some claimants. This combined impact will significantly reduce overall household income for affected claimants

In addition to changes to Disability Living Allowance, it is separately proposed that the Independent Living Fund will be closed and the provision of future support to those reliant on the Fund is uncertain.⁹⁶

Proposed changes to the housing benefit system include reducing the amount of housing benefit paid to claimants if they are living in social housing and are deemed to have surplus bedrooms.⁹⁷ The NIHRC advised the Northern Ireland Assembly on the potential implications of the Welfare Reform Bill on human rights protections in Northern Ireland. In particular the NIHRC advised that proposed changes to housing benefit entitlement could have adverse consequences upon those who require an extra bedroom as a result of a disability.⁹⁸

91 See for example:

Beatty, C. and Fothergill, S. (October 2013): 'The Impact of Welfare Reform on Northern Ireland', (Centre for Regional Economic and Social Research, Sheffield Hallam University for the Northern Ireland Council for Voluntary Action). Available at: http://www.nicva.org/sites/default/files/The%20Impact%20of%20Welfare%20Reform%20in%20NI_2013.pdf

Northern Ireland Assembly Ad Hoc Committee (2013): 'Report on whether the Provisions of the Welfare Reform Bill are in Conformity with the Requirements for Equality and Observance of Human Rights'. Available at: <http://www.niassembly.gov.uk/D970EE65-19CF-440E-8FA7-2E348E3CE455/FinalDownload/DownloadId-C140C98A113345569C3A18A8DFBDD8EC/D970EE65-19CF-440E-8FA7-2E348E3CE455/Documents/Ad-Hoc-Welfare-Reform-Committee/Report/NIA921115.pdf>

A summary of concerns expressed by Church Leaders and Trade Unions on Welfare Reform Bill and its potential impact on Northern Ireland is available at: <http://www.bbc.co.uk/news/uk-northern-ireland-20132024>

Law Centre Northern Ireland (September 2011): 'Evidence to the Work and Pensions Select Committee Proposal to Replace Disability Living Allowance with Personal Independence Payment'. Available at: <http://www.lawcentreni.org/Publications/Policy-Responses/ResponseWPSReplacingDLA.pdf>

Northern Ireland Welfare Reform Group (October 2012): 'The Welfare Reform Bill: Briefing on the key issues for people with disabilities and carers'. Available at: <http://www.disabilityaction.org/fs/doc/publications/disability-and-carers-policy-briefing-on-welfare-reform.doc>

92 Disability Living Allowance is a social security benefit specifically targeted at disabled adults and children to help them with extra costs associated with having a disability addressing care and support requirements of day to day living and mobility requirements. Persons with disabilities could apply for either or both the care component of mobility component of DLA. This allowance also provided a passport to other additional social security benefits such as increased unemployment benefit. This benefit has been replaced, with revised criteria for eligibility, by the Personal Independence Payment.

93 In Northern Ireland Social Security is a devolved matter for the Northern Ireland Assembly however similar legislation under consideration stage at the Northern Ireland Assembly will ensure parity of treatment of all disabled people across the UK. Available at: http://www.dsdni.gov.uk/index/publications/other_reports/equality.htm

94 Department for Social Development (April 2013): 'Welfare Reform Briefing Section 75 Update', (Belfast: DSD). Available at: www.dsdni.gov.uk/welfare-reform-bill-section-75-update-april-2013.doc

25% of those Disability Living Allowance recipients who will be reassessed before October 2015 will not be eligible for Personal Independence Payment and will receive no award while 32% will have their award decreased and 24% are expected to see an increase in their payments. The remaining 19% are expected to see no change. Beatty and Fothergill (see page 14 in reference 105 above) estimate that those losing out as a result of the changeover from DLA to PIP will lose an average of £2,000 per year.

95 Byrne, B., Harper, C., Irvine, R.S., Russell, H. and Fitzpatrick, B. (2014): 'Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD – Draft Final Report 11 March 2014', page 105.

96 OFMdfM 'Closure of the Independent Living Fund – Future Support of ILF Users in Northern Ireland' 4 August 2014

97 A reduction of 14% of eligible rent will apply where there is 1 spare bedroom, and a reduction of 25% of eligible rent for 2 or more spare bedrooms

98 Welfare Reform Bill Northern Ireland <http://www.niassembly.gov.uk/Assembly-Business/Legislation/Primary-Legislation-Current-Bills/Welfare-Reform-Bill/Welfare-Reform-Bill-as-Introduced/> See NIHRC 'Advice to the Ad Hoc Committee on Welfare Reform' 2013

To date, in Britain a number of legal challenges have been launched which have been unsuccessful however other legal challenges remain to be decided on by the courts.

Mental capacity and health legislation

Following the Bamford review⁹⁹, the Minister for Health announced his intention to examine the law relating to mental capacity and consent. In 2009 a consultation document issued by the DHSSPS set out a framework that proposed a “twin track” approach of new mental capacity legislation and mental health legislation with overarching principles.¹⁰⁰

The DHSSPS has developed a draft single legislative framework on mental capacity and consent.¹⁰¹ The proposed system would codify existing common law standards and will introduce a presumption of mental capacity for all persons over the age of 16. There would also be a requirement to demonstrate that an affected person receives support and the opportunity to exercise decision-making.¹⁰² The proposals include steps to be followed and would establish a framework of safeguards for protection from liability for anyone potentially intervening in the care, treatment or personal welfare of another person.

Where a person lacks capacity, a new framework would require decisions on their behalf to be in their best interests. The intention is to create a process that is both robust and flexible. Interventions will be time, issue and decision specific. This would require, inter alia, consideration of changes in a person’s capacity and an assurance of necessary supports.

The proposed framework would set a context for those providing general care for another person where potential decision-making and capacity issues arise.¹⁰³ In addition to its broad application, there would be specific provision for and additional safeguards relating to serious interventions, such as surgery or medical treatment with potential side effects. Where serious interventions are considered, a formal assessment of the person’s capacity by a suitably qualified person would be required. A nominated person would also have to be in place to be consulted on the best interests of the person who is the subject of the proposed intervention. Where a person lacks capacity to nominate a person, the default person would be the carer.¹⁰⁴ If that nominated person objected to the intervention, this in turn would escalate the process and require additional safeguards. At this stage, an Independent Advocate must be put in place and consulted, and authorisation must be obtained from a HSC Trust authorisation panel of 3 suitably qualified people.¹⁰⁵

The higher level safeguards would automatically apply in the case of serious interventions, such as deprivation of liberty or compulsory treatment.¹⁰⁶ The proposed framework also recognises and allows for suspension of the safeguards in urgent situations, such as following a road traffic accident where a person might be

⁹⁹ Bamford Review ‘A Comprehensive Legal Framework for Mental Health and Learning Disability’ August 2007

¹⁰⁰ DHSSPS ‘Legislative Framework for Mental Capacity and Mental Health Legislation in NI’ A Policy Consultation Document January 2009

¹⁰¹ DHSSPS ‘Consultation on Proposals for New Mental Capacity Legislation for Northern Ireland’ May 2014

¹⁰² Ibid.

¹⁰³ Ibid., para 2.25

¹⁰⁴ Ibid., para 2.46

¹⁰⁵ Ibid., para 2.71

¹⁰⁶ Ibid., para 2.54 anon

unconscious. However, after the urgent situation has passed, the process for assessing and assuming capacity would resume.

Finally, the proposed legislation would introduce a new system of “Lasting Power of Attorney” (LPA) to replace the current “Enduring Power of Attorney” system.¹⁰⁷ This will be based on making decisions in the present for the future in terms of registering a LPA in advance rather than when it will be needed or used, and will apply to health and welfare as well as financial matters. It will also introduce a new system of High Court appointed Deputies, and the new framework will be overseen and managed by a new Office of Public Guardian to replace the existing Office of Care and Protection.¹⁰⁸

A public consultation on a draft Bill concluded in September 2014.¹⁰⁹ It is anticipated that the Mental Capacity (NI) Bill will be introduced to the NI Assembly in 2015.

¹⁰⁷ Ibid., para 3.4

¹⁰⁸ Ibid., para 2.12

¹⁰⁹ DHSSPS ‘Consultation on Proposals for New Mental Capacity Legislation for Northern Ireland’ May 2014

Rights based analysis of issues and gaps

In this chapter we present and analyse the findings of our research against the human rights standards set out in chapter 1. The chapter references relevant legislation and makes a number of recommendations.

The right to family life

Having assisted the NIHRC to conduct this research, Carers NI reported that carers who took part in a series of focus groups expressed a fear of separation from those receiving their care. These fears were shared by older carers and child carers. Both groups stated that they often do not seek out the necessary help for fear that the person may be taken away from the family home.¹¹⁰

With respect to parents caring for adult sons and daughters a policy emphasis on care in the community and an increase in the life expectancy of persons with numerous disabilities has led to an increase in the number of older parent carers of adults with disabilities.¹¹¹

As a carer grows older their capacity to continue to provide for the needs of the cared for person diminishes, furthermore they may encounter health problems and require greater assistance to meet their own needs. Research by the University of Ulster identified an increase in the number of parents continuing to care for children with intellectual impairments well into their old age.¹¹² There are particular concerns about the increasing numbers of older people who have for many years supported their disabled sons and daughters at home. A 2009 report from the Changing Ageing Partnership revealed a lack of support for older people who care for adult children with disabilities.¹¹³ The greatest challenges were lack of respite for sons or daughters with disabilities and dealing with their difficult behaviors.

During the course of the NIHRC research, older carers consistently raised concerns regarding worries about the future. This was closely related to their own health and continued ability to care:

I'm worried about my own health. I'm going to just keep on going, but what happens when I hit the wall?

What's next? What's going to happen to my young one when I can't be there for her anymore?

My daughter has no communication skills. Who is going to be able to look after her if something happens to me?

It feels like we're running 10 years ahead – I felt like I had the health and stresses of a 60 year old by the time I was 50.

The research indicates a view that there is a lack of choice for the cared for person, combined with a fear that raising concerns will lead to the cared for person being institutionalised and, as a result, the cared for person will no longer be able to live with their families.¹¹⁴

¹¹⁰ "Older Carers in Northern Ireland: Key Facts" Carers Northern Ireland briefing paper, April 2013 (not available online)

¹¹¹ O Bryantan 'Current and Future Concerns of Older Parents of Sons and Daughters With Intellectual Disabilities'

¹¹² *Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability*. Taggart, L., Truesdale-Kennedy, M., Ryan, A.A., and McConkey, R (2012) *Journal of Intellectual Disabilities*, 16 (3). pp. 217-234

¹¹³ "What the future holds: Older people caring for adult sons and daughters with disabilities", Dillenburger, K., & McKerr, L. Changing Aging Partnership (CAP), Institute of Governance, Queen's University of Belfast, 2009 <http://www.cardi.ie/publications/whatthefutureholdsolderpeoplecaringforadultsonsanddaughterswithdisabilities>; <http://www.qub.ac.uk/research-centres/CentreforBehaviourAnalysis/Publications/>

¹¹⁴ This is an assessment from this research exercise.

The NIHR recommends that the DHSSPS give specific consideration to the concerns and needs of older carers. In particular, raising greater awareness among older carers of the available mechanisms of support should be a priority.

Child carers expressed similar concerns that seeking assistance would result in separation, for child carers the concern was more that they themselves may be taken into the care of the state. A number of child carers provided an account of their experience with social workers:

They do more harm than good. One of them came out and told [the cared for person] off for the house being untidy and made him feel bad. They come and judge you and do not understand – they don't care about why the house is a mess, they were just like 'tidy your house'

The social worker came to our house and just kept writing stuff down and she was judging us.

The preamble to the UNCRC recognises that “for the full and harmonious development of his or her personality, [a child] should grow up in a family environment”. The NIHR recommends that the DHSSPS and the OFMdfM assess the level of support currently provided to families where a child is involved in a caring role.

The right to an adequate standard of living

All individuals have a human right to enjoy an adequate standard of living. To facilitate this, the State must take steps to ensure that persons are able to afford food and housing expenses. Research has demonstrated that caring responsibilities can have negative implications on an individual's ability to maintain an adequate standard of living. “The Cost of Caring” published by Carers UK showed that among the carers surveyed in Northern Ireland between September 2010 and July 2011, 43% had cut back on essentials like food and heating; 68% were in fuel poverty¹¹⁵; 51% said money worries were impacting their health; and 79% had cut back on socialising with friends and family.¹¹⁶ A state of caring survey undertaken by Carers UK between February 2013 and August 2013 in Northern Ireland reported that of those surveyed :

42% were unable to afford their utility bills

46% had been in debt as a result of caring

45% were cutting back on essential spending like food and heating to make ends meet.¹¹⁷

The provision of care often involves a financial commitment and can result in an individual having to give up employment. Whilst the social security system makes provision for carers the results of the Costs of Caring research indicates that this is inadequate.¹¹⁸ Furthermore, it is also reported that the proposed Welfare Reform Bill will lead to greater financial strains on some carers and to greater pressure being placed upon them.¹¹⁹

¹¹⁵ “The Cost of Caring: How money worries are pushing carers to breaking point”, Carers UK, 2011 http://www.carersuk.org/media/k2/attachments/The_Cost_of_Caring_1.pdf

¹¹⁶ Ibid.

¹¹⁷ Caring and Family Finances Carers UK 2014

¹¹⁸ Ibid.

¹¹⁹ ‘Welfare Reform Bill and carers’ Carers UK 2012 : http://www.parliament.uk/documents/joint-committees/human-rights/Carers_UK_Welfare_Reform_Bill.pdf

Noting the additional financial burdens that families with a disabled member and carers may face, the NIHRC recommends that NI Executive programmes aimed at alleviating poverty, including fuel poverty, must take full account of the challenges faced by carers. This matter should be considered by the OFMdFM.

The right to social security

The NI Executive has an obligation towards rights holders who have lost their means of subsistence for reasons beyond their control. Social security provision must cover food, clothing, housing, water and sanitation. The ICESCR Committee has specifically recognised that social security payments to persons with a disability should cover family members and other informal carers.¹²⁰

The NI Executive has sought to meet its obligation towards carers through provision of the Carer's Allowance, in addition a carer may be able to access a range of further benefits, whether regular or one off. Carers have reported throughout the research that they often encounter difficulty in accessing information and advice on benefits to which they may be entitled. The DSD has acknowledged this problem and is attempting to improve benefit uptake amongst carers.¹²¹ There is an obligation to ensure that the social security system is accessible and to ensure that those seeking assistance are able to access information in a clear and transparent manner.

The NIHRC recommends that the DSD intensify efforts to ensure a greater uptake of social security benefits amongst carers.

Carer's Allowance

The Carer's Allowance currently amounts to £61.35 per week. Carers have indicated that this inadequately compensates them either for their time or for the costs associated with caring. The problem was summarised by one participant as follows:

for this princely sum a carer is expected to be on duty 24 hours a day/365 days per week. This equates to 35p per hour. I was somewhat surprised to find that when I reached the age where I qualified for my own old age pension, carer's allowance automatically stopped. I am still on duty 24/7 - 365 days per year. This equates to 0p per hour. How is this legal or possible?

Under the applicable criteria a carer will become ineligible for Carer's Allowance if they earn more than £102 per week. The application of the overlapping benefit rule also means that carers of pensionable age in receipt of the state pension may become ineligible for the Carer's Allowance.¹²²

¹²⁰ See Chapter 2 Committee on Economic, Social and Cultural Rights, General Comment 19, The right to social security (art. 9) (Thirty-ninth session, 2007), U.N. Doc. E/C.12/GC/19 (2008), Para 20

¹²¹ 'Maximising Benefit Uptake 'Maximising Incomes and Outcomes - A Plan For Improving The Uptake Of Benefits' Discussion Document DSD NI December 2012

¹²² While carers receiving State Pension generally cannot also receive CA, because of overlapping benefit rules, if their pension is less than £61.352 per week (the current CA payment) they are entitled to a CA 'top-up' to that amount. In addition, where a State Pension of more than £61.35 is received and the carer meets the eligibility criteria for CA, this 'underlying entitlement' might enable the carer to qualify for the additional amount for carers in Pension Credit (PC).

Carers who took part in the NIHRC research reported that the Carer's Allowance may at times inadequately compensate the cost of caring and will in the vast majority of circumstances significantly under-compensate for the number of hours spent caring. This may result in circumstances where social security payments do not meet the special needs for assistance and other expenses associated with a cared for person's disability.¹²³

The Westminster Parliament Work and Pensions Committee has acknowledged that carers incur costs that are not compensated through the Carer's Allowance or other benefit entitlements which the cared for person may be able to avail of.¹²⁴ The Committee recommended the development of a two-tier support system for carers. First, a 'Carer Support Allowance' should be introduced to be paid at the same level as Jobseeker's Allowance, this should not be means-tested. Second, a 'Caring Costs Payment' should be available to all carers in intensive caring roles to compensate them for the additional costs of caring.¹²⁵

The ICESCR Committee makes clear that governments must take measures to ensure the social security system provides adequate subsistence.¹²⁶

In general carers receiving State Pension cannot also receive Carer's Allowance, due to the overlapping benefits rule. However if their pension is less than £61.35 per week they are entitled to a Carers Allowance 'top-up' to that amount. In addition, where a State Pension of more than £61.35 is received and the carer meets the eligibility criteria for Carers Allowance, this 'underlying entitlement' might enable the carer to qualify for Pension Credit.¹²⁷

This research identified that reduced benefit entitlements as a result of the overlapping benefit rule amongst carers of pensionable age may restrict their ability to meet their living costs, which can increase with ageing.¹²⁸

Noting that costs associated with the provision of caring may be significant, the NIHRC recommends that the DSD evaluate whether the Carer's Allowance adequately compensates carers for the cost of caring in all circumstances.

Welfare Reform

To be eligible for Carer's Allowance, a carer must be caring for someone in receipt of a 'qualifying disability benefit', including DLA at the middle or higher rate care component.¹²⁹ The Welfare Reform Bill proposes the introduction of Personal Independence Payment which will replace DLA for all working aged disabled people by 2018.¹³⁰ In Northern Ireland just over 1 in 10 of the population are in receipt of DLA.¹³¹ The DSD conducted an exercise in testing DSD claims against PIP assessments. Based on this the Department estimated that 25% of claimants will lose entitlement altogether when transferring from DLA to PIP, 32.8% will retain benefit

¹²³ DWP 'Household finances of Carer's Allowance recipients' July 2014 available at: <http://www.york.ac.uk/inst/spru/pubs/pdf/rrep875.pdf>

This research identified that Carer's Allowance was a vitally important part of household income which is used to provide both everyday expenditure and the additional costs incurred.

¹²⁴ House of Commons Work and Pensions Committee (2008). Valuing and Supporting Carers. Fourth Report of Session 2007-08 HC 485-I Published on 29 August 2008

¹²⁵ *Ibid.*, pg 52

¹²⁶ See Chapter 2

¹²⁷ See DWP 'Household finances of Carer's Allowance recipients' July 2014 available at: <http://www.york.ac.uk/inst/spru/pubs/pdf/rrep875.pdf> pg 15

¹²⁸ See further: Elaine Argyle 'Poverty, Caring and Older Age' available at: http://www.sheffield.ac.uk/polopoly_fs/1.714181/file/elaine.pdf

¹²⁹ *Ibid.*

¹³⁰ Carers UK 'Caring & Families Finances Inquiry' 2013 pg 116

¹³¹ See DRDNI 'Northern Ireland

Personal Independence Payment Information

Booklet' March 2013 <http://www.dsdni.gov.uk/ni-pip-information-booklet.pdf>

but, at a lower rate, 18.8% will retain at the same rate of benefit, and 23.3% will be on a higher rate after transferring.¹³²

The move to PIP will therefore result in a significant number of carers no longer being eligible for Carer's Allowance. Many households will therefore face the dual impact of the cared for person no longer receiving DLA and the carer no longer receiving Carer's Allowance. Participants in the NIHRC research were aware of this risk and the significant impact it could have on household incomes. It was felt that the proposals had not considered the cumulative impact on the ability of households to afford the costs of housing and household essentials. Carers UK has identified that carers of working age, disabled partners and parents of adult disabled children will be the groups most affected by the cuts to disability benefit spending.¹³³

Participants in the NIHRC research spoke of the stress caused by the proposed new models of reassessment and recounted negative experiences of how their loved ones' abilities and disability were being considered:

they have to go through a medical. Why do they have to be assessed when they have a disability, by someone who isn't qualified to assess them?

A number of participants in the focus groups expressed concern at the enhanced assessment process for PIP that will replace DLA. The carers of persons with lifelong or degenerative illnesses were frustrated at the proposed requirement to regularly review the support requirements of the individual.¹³⁴ A particular concern raised, was that the new assessment process would not appreciate the role played by carers in receipt of the Carer's Allowance and their role in ensuring the person with a disability is able to live in dignity.

The NIHRC recommends that the potential impact of welfare reform proposals must be analysed by the DSD to ensure the proposals do not adversely impact on the ability of families currently in receipt of DLA and Carer's Allowance to enjoy an adequate standard of living. This should entail examining whether a fund to ameliorate the impact of these changes for people adversely affected and their carers should be introduced. In circumstances where there are significant costs arising from a person's disability and in the provision of care, the potential for families to encounter difficulties in affording heating and food must be considered.

The right to work

ICESCR, Article 6 guarantees to everyone "the opportunity to gain his/her living by work". The NI Executive must promote and facilitate the right to work. This obligation can be met through introducing legal obligations on employers and through direct support to the carer and cared for person, such as respite care. The NIHRC research indicates that carers have given up employment due to inflexible working practices and due to the absence of provision for alternative care.

Of the Northern Ireland respondents to the Carer's UK State of Caring survey, 48% stated that they had given up employment to provide informal caring.¹³⁵ In addition, 31% of respondents indicated that they had reduced working hours and 20% stated that they had taken a less qualified job.¹³⁶ Carers UK has identified that the

¹³² NI personal Independence Payment Information Booklet Issued by DSD Analytical Services Unit March 2013

¹³³ Carers UK 'Caring & Families Finances Inquiry' 2013 pg 121

¹³⁴ Department for Work and Pension 'Simplifying the welfare system and making sure work pays (2013)

¹³⁵ Carers UK 'State of Caring 2013' available at <http://www.carersuk.org/professionals/resources/research-library/item/3090-the-state-of-caring-2013> The results of the State of Caring Survey were based on the responses from 3000 Carers who completed a survey from Carers UK into the state of caring in 2013

¹³⁶ Ibid.

impact of ceasing employment prior to retirement age has adverse implications on an individual's quality of life once they reach pensionable age, leaving two thirds of pensioners worse off with implications for their ability to maintain an adequate standard of living in older life, in particular where costs of caring are high.¹³⁷

The proportion of carers who cease employment, reduce hours or work in less qualified posts to ensure they are able to meet their caring responsibilities is a source of concern. It is noted that enhanced protection for carers from harassment and discrimination in the workplace has been provided in Great Britain by way of the Equality Act 2010. Similar provision has not however been introduced to Northern Ireland.¹³⁸

Furthermore, while there are numerous entitlements in relation to flexible working and emergency leave for carers, Carers NI has raised concerns regarding their implementation in the employment context. Carers NI's advice service regularly receives queries from working carers who are experiencing difficulties with getting time off to take the people they look after to medical appointments.¹³⁹ They report that employers seem to be confused about what evidence is needed to demonstrate that someone is a carer; in a worst case scenario asking for the cared for person's medical records. There appears to be a lack of awareness amongst employers of their obligations with respect to flexible working arrangements.

Carers UK report that a significantly higher proportion of carers in households with paid income were able to afford their basic bills, 72%, compared to 57% of those where no-one was in paid work.¹⁴⁰ The ability to exercise the right to work can therefore contribute towards the enjoyment of other rights, including the right to an adequate standard of living.¹⁴¹

Noting the obligation to adopt legislation or to take other measures to ensure equal access to work for carers, the NIHRC recommends that the NI Executive, and in particular the Department for Employment and Learning (DEL), consider taking steps to enhance legal protections for carers seeking to exercise the right to work. In addition DEL should work with employers and carers organisations to develop resources for exit interviews for carers leaving work so that individuals can be signposted to advice and support. This should also be available to people of working age whose caring responsibilities have recently come to an end.

The NIHRC notes that the impact of restrictive access to employment opportunities can have long-term detrimental implications for child carers. The Children's Society has found that there is *"a clear association between being a young carer and having lower job prospects and educational opportunities between 16 and 19, and between being a young carer and the likelihood of being in lower skilled occupations at age 20/21"*.¹⁴² This finding underscores the need to ensure appropriate support for child carers to obtain employability skills by way of experience and training.

Noting the reality that child carers encounter difficulties in obtaining qualifications and employability skills, the NIHRC recommends that the DEL prioritise support for child carers in relevant educational initiatives. The Department of Finance and Personnel should consider how

¹³⁷ Ibid.

¹³⁸ ECNI 'Keeping pace with the changes in GB' see <http://www.equalityni.org/Delivering-Equality/Addressing-inequality/Law-reform/Research-investigations/keeping-pace-with-the-changes-in-Great-Britain>

¹³⁹ Information provided by Carers NI

¹⁴⁰ Carers UK 'State of Caring 2013' available at <http://www.carersuk.org/professionals/resources/research-library/item/3090-the-state-of-caring-2013>

¹⁴¹ Ibid.

¹⁴² Children's Society 'Hidden from View : the experience of young carers in England' May 2013 available at http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf pg 13

procurement policies can be used to encourage support for carers to be further embedded in the workplace.

The right to education

The NI Executive is obliged to guarantee to everyone the right to an education. This right is particularly important to children and is protected by the UNCRC and the ECHR. It is important to note however that the right to secondary education includes technical and vocational training and that an individual can exercise this right at any stage in their life.

Research carried out in England has indicated that child carers have significantly lower levels of educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine Bs and nine Cs.¹⁴³ Carers in Northern Ireland have similar concerns regarding educational underachievement.¹⁴⁴ Child carers taking part in this research stated that they often have difficulty concentrating in school because they are worried about the provision of care to the cared for person during their absence:

Teachers tell you off because I don't think they understand, even though you tell them everything and I feel like saying 'you try to do the homework'

I am happy to help but sometimes it can get really stressful especially if you do have a lot of coursework or something at school

When I'm at school I worry if [the cared for person] is ok. It's not as bad as it used to be – when I was at primary school I used to pretend to be sick so I could go home and see if he was ok

Child carers report that they often do not have sufficient time to study due to their caring commitments. Child carers are also reluctant to commit to extra-curricular activities essential to developing skills and gaining experience for higher education and employment. This is because they do not want to be away from the cared for person for too long.

Like X was saying she worries, sometimes the worry takes over and is too much. It's really confusing because I do worry but then I know I am worrying too much and I can't stop worrying too much and it gets really confusing

The status of a student as a carer seems to have greatest impact during periods of transition, in particular when making decisions about vocational training or tertiary education. It was reported that at a particularly important and worrying time in their lives, when decisions are being made about college, careers and life more generally, there is an increased need for suitable and appropriate services for children that is not being provided.

¹⁴³ Children's Society 'Hidden from View : the experience of young carers in England' May 2013 available at http://www.childrensociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf pg 12

¹⁴⁴ Expressed during this research

I want to do something with languages and [the cared for person] says I should do that. I would want to go somewhere quite close and I was looking online and you can do language courses in Coleraine or Belfast. I wouldn't like to be in England or somewhere because then I couldn't just get a train or a bus if something happened

The NI Executive has a duty to facilitate an individual's access to education. This may include the introduction of positive measures. Enabling an individual, and in particular a child, to engage fully and effectively in education will in many cases require the provision of alternative care for the cared for person. This may be on a temporary or semi-permanent basis.¹⁴⁵

The NIHRC notes that the existing procedure for the carrying out of a Carer's Assessment refers to educational commitments.¹⁴⁶ Furthermore, assessments of need under the Children (NI) Order 1995 will consider educational commitments.¹⁴⁷ However, concerns regarding educational under-achievement of child carers suggest that neither of the two procedures fully address the obstacles facing child carers.¹⁴⁸

The Department of Education should create a statutory duty on educational bodies to support young and student carers.¹⁴⁹ Noting concerns regarding educational achievement amongst carers, the NIHRC recommends that further research be carried out into this matter. Such research should consider the application of the Carer's Assessment and Children (NI) Order 1995 to determine if both mechanisms are sufficiently robust.

The right to health

The ICESCR recognises that everyone is entitled to the highest attainable standard of physical and mental health. The NIHRC research indicates that caring responsibilities may have adverse implications for both the physical and mental health of the carer. Carers UK has reported that over half of all carers have a caring related health condition.¹⁵⁰ The ICESCR Committee has recognised that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can live a healthy life. As caring responsibilities are acknowledged as a factor which potentially undermines the enjoyment of good health the state must take action to alleviate the burden on carers.¹⁵¹

To meet its obligations towards carers the NI Executive must have in place robust systems to identify individuals with caring responsibilities. However, health professionals who took part in this research were aware that there is a significant gap between the number of people identified in the census that said they provided care, and the numbers that are identified and registered as carers. There is a heavy reliance on General Practitioners (GPs) to identify carers and an apparent lack of consistency of approach by and between GPs, and within and across HSC Trusts. GPs are financially incentivised to register carers, but they are not

¹⁴⁵ Dr Joe Sempik and Professor Saul Becker 'Young Adult Carers at School: Experiences and Perceptions of Caring and Education' Young Carers International The University of Nottingham 2013 pg 11 Noted that many young carers experience absence or lateness from school due to caring responsibilities.

¹⁴⁶ DHSSPS 'Carers and Direct Payments Act (NI) 2002 Carers' Assessment and Information Guidance' 2005 para 2.42

¹⁴⁷ Children (NI) Order 1990 Article 18

¹⁴⁸ Patient Client Council 'Young Carers in Northern Ireland: Report of the experiences and circumstances of 16 year old carers' June 2011 available at: http://www.patientclientcouncil.hscni.net/uploads/research/Young_carers_in_Northern_Ireland.pdf 'The implications are clear; the more time spent caring, the less time can be devoted to schoolwork, which in turn can have a negative effect on academic performance. The numbers are, however, too low to draw any definite conclusions, but highlight a group of young people who may be at risk from losing out educationally and may be in need of additional support.'

¹⁴⁹ See Education (Additional Support for Learning) (Scotland) Act in 2004, as amended

¹⁵⁰ Carers UK, Missed Opportunities: the impact of new rights for carers, Carers UK June 2003.

¹⁵¹ Commission for Social Care Inspection (2006) *The state of social care in England 2005-06*. London: CSCI at para 7.106

incentivised to keep the register up to date.¹⁵² A number of those who took part in this research suggested that GPs should be more pro-active in identifying carers and suggested that the obligation to identify carers should form part of the General Medical Services contract.¹⁵³

There is a concern regarding the provision of healthcare information to carers. The Carers and Direct Payment Act places a duty on health and social care authorities to make information available¹⁵⁴, and yet there is a reported gap between policy and practice. While acknowledging that there were some areas of good practice, it was suggested that:

things have stood still. Providing information is more than booklets and leaflets, doctors and nurses. We need to move beyond this. Why are we not doing it?

The health and social care representatives involved in this research recognised significant obstacles with respect to the effective identification of carers and provision of information. There is also a problem with record keeping. The HSC Trusts operate different data systems, they use different criteria to count the same event, and there are different policies in place regarding data collection. By way of example, not every HSC Trust maintains a register of carers because they believe there are ethical issues with retaining information on people. These differences lead to an inconsistency across the jurisdiction. It also results in the authorities being unable to appreciate the extent of their obligations with respect to the caring population and to respond accordingly. If HSC Trusts are not aware of the levels of need in their areas they will not be able to budget and allocate the resources required.

In August 2012 a report by the Regulation and Quality Improvement Authority (RQIA) on the carer's component of Northern Ireland Single Assessment Tool,¹⁵⁵ found that:

information on unmet need in trusts is currently collected manually from various sources and locations. However, information on unmet need consists mainly of numbers of people awaiting services, rather than reflecting the complexity of identified needs.¹⁵⁶

Audit findings indicated for example that there was no unmet need being recorded in over 60 per cent of completed carer assessments. The RQIA concluded that:

the failure to have a regional working definition of unmet need for trust frontline staff has led to confusion among staff groups and this has led to inconsistent data collection within trusts. Consideration should be given to drawing up a regional definition of unmet need in order that services for carers can be appropriately commissioned.¹⁵⁷

The RQIA recommended that the collating and reporting of unmet need should be reviewed by the HSC Board and that staff in the HSC Trusts should ensure that unmet need is adequately recorded to ensure that services can be planned, commissioned and developed appropriately and that the HSC Trusts are aware of the gaps in

¹⁵² See 'Supporting Carers: An action guide for general practitioners and their teams' has been released by the Princess Royal Trust for Carers and the Royal College of General Practitioners.

¹⁵³ The General Medical Services (GMS) contract is the name used to describe the medical services provided by GPs in contract with the NHS. See http://www.dhsspsni.gov.uk/index/hss/gp_contracts.htm

¹⁵⁴ Carers and Direct Payments Act (Northern Ireland) 2002 section 7

¹⁵⁵ "Review of the Implementation of the Northern Ireland Single Assessment Tool; Stage Two: Carer's Support and Needs Assessment Tool", Overview Report, Regulation and Quality Improvement Authority (RQIA), August 2012 http://www.rqia.org.uk/cms_resources/NISAT%20Review%20%20Phase%201wo.pdf

¹⁵⁶ Ibid.

¹⁵⁷ Ibid.

service provision.¹⁵⁸ It was suggested during the course of the research that these recommendations have not yet been fully acted upon.

To meet its human rights obligations towards carers the NI Executive must have up to date information on the health needs of carers and must have in place robust mechanisms for the identification of carers. Without mechanisms for the identification of carers, a carer can be left in a situation that undermines their right to health. Article 31 of the UNCRPD places a specific obligation “to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [UNCRPD]”.

The NIHRC recommends that current mechanisms for the recording of the number of carers in HSC Trusts be reviewed to ensure that they are sufficiently robust and consistent across the jurisdiction. The DHSSPS should also place greater emphasis on the collection of information on the health and wellbeing of carers to enable early interventions.

Carer's Assessment

The Carers and Direct Payments Act (Northern Ireland) 2002 affords carers the entitlement to request an assessment of their ability to continue to provide care. This is an important initiative and has the potential to address many of the conditions that can undermine the enjoyment of the right to health by carers.¹⁵⁹ However, carers reported during the course of the research that they often encounter difficulties in obtaining an assessment and that the outcomes often fail to address the conditions necessary in order to fulfil the right to health.

The DHSSPS publish quarterly statistics on carer's assessments, and on this basis it appears that the number of assessments in proportion to the number of carers is relatively low.¹⁶⁰ The Commissioner for Older Persons in Northern Ireland has reported a low level of uptake of carer's assessments amongst older carers.¹⁶¹

A carer's assessment is an opportunity for a carer to consider their own emotional and practical needs.¹⁶² It can result in the allocation of services or support arrangements and may help prevent a deterioration in both the physical and mental health of the carer. However, there are concerns regarding the carer's assessment. For example, health and social care staff have acknowledged that there is a problem with carers not being informed of their right to an assessment and that they are not always carried out correctly.¹⁶³ This view is supported by the RQIA's 2012 report, which noted that “*interventions arising from an assessment were*

¹⁵⁸ Ibid.

¹⁵⁹ Commissioner for Older Persons 'Supporting Older Carers Examining the reasons for the low level of uptake of Carers Assessments by Older Carers in Northern Ireland' June 2014

¹⁶⁰ DHSSPS 'Carer's Statistics for Northern Ireland: Quarter Ending 30 September 2014' November 2014

¹⁶¹ Commissioner for Older Persons 'Supporting Older Carers Examining the reasons for the low level of uptake of Carers Assessments by Older Carers in Northern Ireland' June 2014

¹⁶² Review of the Implementation of the Northern Ireland Single Assessment Tool; Stage Two: Carer's Support and Needs Assessment Tool", Overview Report, Regulation and Quality Improvement Authority (RQIA), August 2012 pg 17

¹⁶³ For adult carers, the current assessment process is via the carers' component of the NI Single Assessment Tool (NISAT). This 12 page document – which can be seen at <http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm> – contains questions on living arrangements, the type of care and support given, the health of the carer, how caring affects them, any support they receive, any other commitments they have, their financial situation, the future, and contingency planning, before assessing and outlining support or need that has been identified. Examples of such support might include respite, help with household duties, or other breaks or emotional support. It also includes a section for recording unmet need – as will be discussed later in the report there is currently a lack of clarity around the definition and methodology of recording this.

narrowly focused".¹⁶⁴ In particular the RQIA found that less than 1% of assessments audited made any reference to the provision of specific emotional support for carers.¹⁶⁵

Carers NI has identified a number of factors underpinning the reluctance, first to offer a carer's assessments, and second, to ensure that assessments are conclusive. The overriding problem is an apparent fear and reluctance among health and social care staff to offer assessments in case it leads to unsustainable demands for resources and services. Officials interviewed for this research stated:

[colleagues think] carers will beat their door down and they will be swamped.

the policies encourage early intervention and prevention but on the ground resources are tight and competing against emergency provisions. We know that accessing services such as flexible respite at the right time is key, but we also know that carers feel they are pleading and fighting to get them.

It was reported during the course of this research that staff often do not appreciate the value of assessments and that a "seachange" in attitudes was needed away from "I have to offer you this" and towards viewing assessments as beneficial and positive measures directed to prevent costly, crisis situations, from occurring.

Some carers reported that they had not had an assessment; and many said they had not been aware, or were not informed that they were entitled to one; most said they had to fight to get it.

I had to ask for one, it wasn't offered

I fought to get an assessment, it didn't get me anywhere

Fighting your own corner to get an assessment

The Trust should follow you up – they know you're looking after someone – you shouldn't have to chase them.

The research identified that carers may feel they are discouraged from requesting an assessment, or, that the language and tone used by the health and social care staff is negative when it comes to carer's assessments. The result is that some people have been left with a sense that there is no point in applying for an assessment.

I kept asking for one for two years and they kept putting me off. I then wrote to them and said I assumed I had one but hadn't seen it so could I have a copy. The social worker came out then and said she had done one but it wasn't formal so she would do it now. I still haven't seen a copy of it.

The experience of the assessment process itself was equally mixed. Some found the assessment beneficial.

carer's assessment was a positive experience and resulted in more assistance and support. [The social worker] took a personal interest in me and unmet need was recorded.

¹⁶⁴ Review of the Implementation of the Northern Ireland Single Assessment Tool; Stage Two: Carer's Support and Needs Assessment Tool", Overview Report, Regulation and Quality Improvement Authority (RQIA), August 2012 pg 33

¹⁶⁵ Ibid.

I had a good social worker who checked in on me every six months. The second time was much better – the process was fully explained and I felt more involved.

For most others the process was not positive.

The experience was awful.

I have suffered and endured two assessments – both were a totally pointless exercise.

It felt like I was having a test [of my competence to care] and I was re-living the experience.

Quick step in, step out that kind of thing.

It was very vague 'you can't have that', it was all a bit vague.

I was given a piece of paper to fill in by the social worker. There was too much going on in my life and I didn't know what I wanted or needed.

Whether they are any good depends on who is doing it.

As regards outcome, again the reports were somewhat mixed.

I didn't hear anything back from my assessment

Achieved absolutely nothing

I got no feedback on my assessment

They gave me a block of complementary therapies, but it was a block of six and that was it

It seemed to focus on my son's needs so nothing happened

I didn't need the services being offered.

In relation to accessing services and support, either from the assessment process or in addition to it, a recurring theme from carers is the sense of having to 'fight, argue and struggle' to get things done.

Your whole life seems to be a fight. My husband says you're always on the phone, every morning, but I need to be.

Nobody came and rapped the door and asked did [the cared for person] want to go out. I had to look for it.

Inadequacies within the carer's assessment process risk undermining the ability of the NI Executive to meet its obligations towards carers to ensure access to health services. For instance, one of the outcomes of a carer's assessment is the provision of respite. Respite care allows time for a carer to access basic preventative, curative and rehabilitative health services. However, it appears that carers often have to delay health treatments due to an absence of appropriate respite care.

Not every carer will of course want an assessment, or feel they need support. Often there is a reported reluctance or fear of appearing officially on the social services system.¹⁶⁶ Also, the terminology of “assessment” may dissuade some carers who think it will be a test of their caring ability.

Difficulties in monitoring uptake are compounded by the absence of an electronic system for recording numbers of assessments, which is currently carried out manually. Again there are notable differences in systems across HSC Trusts which may go some way to explaining the disparities. However, only so much of the problem identified can be attributed to these factors.

In 2011 the Law Commission produced a report ‘Adult Social Care’, which included detailed analysis of the arrangement for a carer to obtain a carer’s assessment in England & Wales.¹⁶⁷ The Law Commission stated:

the current legal framework for carers’ assessments is fragmented, overlapping and confusing for [decision makers] and carers alike.¹⁶⁸

Examination of practices and procedures show that many of the difficulties that the Law Commission identified in England & Wales are equally present in Northern Ireland. The test laid down in the 2011 Act and the comparative legislation for England & Wales, namely the ‘substantial and regular test’ is unclear, confusing and complex.¹⁶⁹ In addition, the mechanism for requesting an assessment is overly bureaucratic and may deter many carers from accessing an assessment. The Law Commission concluded:

In our view the better approach is to provide that a carer’s assessment is triggered where a carer appears to have, or will have upon commencing the caring role, needs that could be met by the provision of carers’ services or services to the cared-for person.¹⁷⁰

The Law Commission further recommended improvements to the carers assessment, with greater co-ordination of assessments of the needs of the cared for person. In particular it was suggested that greater consideration should be given to whether the carer works or wishes to work or wishes to undertake education, training or any leisure activities.

The psychological health implications of caring have more significant impact for older carers, who experience twice the level of stress of the general population.¹⁷¹ The increased physical demands of caring for a child who has progressed to adulthood can impact on the ability of a parent to care. It must also be recognised that as a child progresses to adulthood his/her parents will be progressing to pensionable age and their physical abilities to provide caring may deteriorate.¹⁷² Research by Sheffield Hallam University has found that the needs of older carers are complex and must be addressed through bespoke packages that take into account their personal abilities.¹⁷³

¹⁶⁶ See specifically relating to older people the Commissioner for Older Persons ‘Supporting Older Carers Examining the reasons for the low level of uptake of Carers Assessments by Older Carers in Northern Ireland’ June 2014

¹⁶⁷ The Law Commission ‘Adult Social Care’ (LAW COM No 326)

¹⁶⁸ Ibid., Pg 68

¹⁶⁹ Ibid., pg 69

¹⁷⁰ Ibid.

¹⁷¹ “Older Carers in the UK” Carers UK and Sheffield Hallam University, 2005 http://www.carersuk.org/media/k2/attachments/Older_Carers_in_the_UK.pdf

¹⁷² Bernadette Stiell, Lucy Shipton and Sue Yeandle A report for Carers UK and Contact a Family from the Centre for Social Inclusion, Sheffield Hallam University Caring for Sick or Disabled Children: Parents’ experiences of combining work and care 2006

¹⁷³ Ibid.

Caring was a full-time job for 90% of the older participants in the Sheffield Hallam University research, and physical care was required in 86% of the cases. Many older carers have been providing caring long term and the potential implications for the health of carers in such circumstances has been highlighted. There is an obligation to ensure the provision of equal and timely access to basic preventative treatments, if an individual's caring responsibilities are prohibiting them from accessing health care.

Greater support for carers to enable them to address their health needs, both physical and mental is required to ensure that the right to health is fulfilled. The carer's assessment is the principal mechanism for addressing circumstances that may result in a carer's health deteriorating and for facilitating a carer to address such problems. In particular, the provision of respite care may be necessary to facilitate timely access to preventative, curative and rehabilitative services.

Noting the important role played by the carer's assessment in the fulfilment of the NI Executive's human rights obligations towards carers, the NIHRC recommends:

- 1. that the DHSSPS assess how effectively HSC Trusts are meeting their duty to ensure all carers are made fully aware of their right to seek a carer's assessment;**
- 2. that human rights considerations be fully integrated within the process for determining what supports are to be provided to carers by HSC Trusts. In particular, decision makers should be required to consider obstacles to carers fully enjoying the right to health, the right to education, the right to work and the right to maintain an adequate standard of health and well being;**
- 3. where an obstacle to full enjoyment of a right is identified the decision maker should be required to demonstrate what supports have been put in place to address this;**
- 4. greater provision should be made by HSC Trusts for reviewing the effectiveness of supports put in place;**
- 5. a carer's assessment should specifically consider whether the carer requires preventative treatments;**
- 6. specific consideration should be given to the rights of children aged 16 or 17 who undergo a carer's assessment;**
- 7. DSD and DHSSPS should develop arrangements so that any successful claim for Carer's Allowance can lead to the claimant being given advice and support to apply for a carer's assessment where one is not already in place.**

Child/Young Carers Needs Assessment

A child carer may be considered a child in need under the Children (NI) Order 1995. The Children and Families Act 2014 makes provision in England & Wales for a "young carer's needs assessment". The then Secretary of State for Education in England, Michael Gove MP, stated.

it will consolidate and simplify the legislation relating to young carers' assessments, making rights and duties clearer to both young people and practitioners; the right to an assessment of needs for support will be extended to all young carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it; make it clear to local authorities that they must carry out an assessment of a young carer's needs for support on request or on the appearance of need, and provide the appropriate links between children's and adults' legislation to enable local authorities to align the assessment of a young carer with an assessment of an adult they care for..¹⁷⁴

It is noted that comparative provisions have not been introduced to Northern Ireland.

A young carer assessment includes an evaluation of whether it is appropriate for the young carer to continue to provide care for the person in question. It places a duty on the local authority to consider the young carer's participation in education, training, recreation and employment.¹⁷⁵ The local authority must also ensure the participation of the young carer, their family and other persons who support the carer.

Considering the impact which caring responsibilities will have on a child, specific provision is required to ensure that the NI Executive is fulfilling its human rights obligation towards child carers. The NIHRC recommends that the DHSSPS introduce a child carer assessment similar to that operating in England and Wales.

The right to participation

Participation is recognised as a specific entitlement in certain contexts and as a core principle that informs the general application of all human rights.¹⁷⁶ The right to participation is specifically protected by the UNCRC, Article 12. The UNCRPD, Article 12 also seeks to ensure the full participation of persons with disabilities in society. It requires the State to recognise the legal capacity of a person with a disability and to ensure they are able to exercise this capacity with appropriate support taking account of their will and preferences.¹⁷⁷ The UN Committee responsible for overseeing compliance with the UNCRPD has recognised the role of those who care for a person with a disability in supporting them to take decisions.¹⁷⁸

Carers reported that they felt that they were viewed predominantly through or in the context of the person that is cared for, rather than as people with their own identities, rights and needs. A particular issue highlighted by carers was the absence of adequate recognition for their rights when making provision for the cared for person to move from one programme of care to another, such as from child to adult services.

Carers generally felt that empowering the cared for person and carers to take decisions would lead to positive outcomes. In particular, they reported a better experience when in receipt of direct payments to arrange respite or other services themselves.¹⁷⁹ Carers suggested that direct payments allowed for flexibility. It is noted that reforms to health and social care provision will increase the use of direct payments.

¹⁷⁴ DEPARTMENT FOR EDUCATION Written Ministerial Statement Children and Families Bill – Young Carers The Secretary of State for Education (Rt Hon Michael Gove MP):

¹⁷⁵ Children and Families Act 2014 section 96

¹⁷⁶ For more detailed information see UNDP, *A Human Rights-based Approach to Development Programming in UNDP*, 23 May 2002. Available at: <http://www.undp.org/content/dam/aplaws/publication/en/publications/democratic-governance/dg-publications-for-website/a-human-rights-based-approach-to-development-programming-in-undp/HR_Pub_Missinglink.pdf> (accessed 10 December 2012).

¹⁷⁷ UNCRD Committee 'Draft General Comment on Article 12' CRPD/C/11/4 Para 41

¹⁷⁸ Ibid.

¹⁷⁹ Carers and Direct Payments Act (Northern Ireland) 2002 section 8

Officials noted that reforms to health and social care provision will increase the use of direct payments. A move outside traditional structures will result in a process whereby a person's needs are assessed and costed, with an amount of funding marked according to level of need. This will then be allocated to them to spend in a way best suited to the individual requirements. It was considered that this move will help address some of the problems faced by carers and the cared for person in accessing services appropriate to them, as well as reducing the demands on the system itself. It was also suggested that this may potentially reduce costs.

The NIHRC has found that the right of the carer and the cared for person to participate is not fully considered when decisions are taken regarding support for the cared for person. The NIHRC notes that enhanced participation of cared for persons can lead to positive outcomes for both the carer and cared for person. The NIHRC recommends that the DHSSPS review the current processes to ensure that enhanced provision for direct payments in the health and social care system are accompanied by increased participation in decision making. Further, the DHSSPS should assess the level of support and advice provided to those who are managing direct payments.

The Children and Families Act 2014 introduced a duty on local authorities in England & Wales to take reasonable steps to identify the extent to which there are young carers within their area who have needs for support.¹⁸⁰ It is noted that there is no comparative provision in Northern Ireland.

The NIHRC recommends that the DHSSPS consider introducing a duty on the HSC Trusts to identify the extent to which child carers have needs for support. Assessment mechanisms should ensure adequate participation of the child in decision making processes.

As set out previously "persons with dependants" is identified as a protected group under section 75 of the Northern Ireland Act 1998. In analysing equality impact assessments undertaken on policies and proposals Carers NI noted confusion around the inclusion of carers. For example, the Equality Impact Assessment of the draft Disability Strategy (2012-2015) published by the OFMDFM considers the impact on persons with and without children. However it does not more generally consider the impact on persons with dependents, which would be in keeping with the wording of section 75.¹⁸¹

Noting the reported lack of clarity on the inclusion of carers in the section 75 protected categories the NIHRC recommends that the OFMDFM engage with the ECNI and that consideration be given to issuing guidance to all NI Executive departments to ensure that the rights of carers are appropriately considered.

¹⁸⁰ Amendment to the Children Act 1989 insertion of section 17ZA

¹⁸¹ "A strategy to improve the lives of disabled people 2012-2015", OFMDFM, March 2012 http://www.ofmdfmi.gov.uk/final_disability_strategy_consultation_doc_with_amended_foreward_as_agreed_-_2.04.12_to_go_before_executive_on_5.04.12.pdf see page 53

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