SHRC
Scottish
Human Rights
Commission

Chapter 1: Dignity and care

Getting it Right?
Human Rights in Scotland

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Theme 1: Dignity and Care

Introduction

The Scottish Human Rights Commission (SHRC) seeks to empower people to know and claim their rights, and to increase the ability and accountability of public and private bodies to deliver on human rights in Scotland. In support of these goals SHRC promotes the evidence based and inclusive development of Scotland's National Action Plan for Human Rights – a road map to the further realisation of all human rights in practice in Scotland.

The report as a whole presents a summary of some of the key gaps and good practices which have emerged from a scoping project undertaken by the SHRC. This specific section summarises the findings relating to theme of Dignity and Care. It is not intended to be a comprehensive 'state of human rights in Scotland' report, but a prompt for discussion in the development of Scotland's National Action Plan for Human Rights. With this in mind, individuals and organisations are encouraged to consider their views in response to two key questions as they review this thematic section:

> **1. Based on the evidence presented in the report *Getting it right? Human rights in Scotland*, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?**
>
> **2. What specific and achievable actions do you consider would best address the concerns you identify in your response to question 1?**

Scoping Project Methods Summary[1]

The data collection began in 2010 and was divided into two phases - a first phase focussing on collating and analysing a range of secondary data sources[2] and a second phase where SHRC convened a series of small focus groups and in-depth interviews with a range of communities, groups and individuals in Scottish society.[3] In line with the SHRC's statutory mandate, particular attention was given to hearing from those who tend to be marginalised and whose voices are less often heard in mainstream debates surrounding human rights. In taking this approach SHRC sought to put a 'human face' on the issues uncovered in the scoping project.

Introduction to Dignity and Care

This thematic section explores the theme of 'Dignity and Care' in Scotland, which is one of the eight themes which emerged from the research review. The theme is broad, to enable coverage of a range of issues which were identified following a prioritisation process,[4] including the quality of care, independent living, self-determination and carers' rights. Some related topics have been considered in other thematic sections, including abuse prevention, protection and remedy (under "Safety and Security"), mental health care and treatment (under health) and mental health detention (under living in detention).

The focus of this scoping project has primarily been on issues of human rights concern that are within the competence of the Scottish Parliament. Across all thematic areas, there are some, often complex issues, which raise issues of concern that are devolved, whilst others are reserved to Westminster,[5] including equality legislation. The Equality Act 2010, however, dose place a duty on the Scottish Government to abide by the public sector equality duty,[6] which could bring about a more substantive role for Scottish equality duties in the future.[7]

In relation to the safeguarding of those in receipt of care services in Scotland, the Care Inspectorate[8] carries out both unannounced and announced inquiries to monitor compliance with the National Care Standards [NCS] and investigates complaints. The general principles of the Care Inspectorate are: the protection and enhancement of the safety and wellbeing of all persons who use, or are eligible to use any social service; the promotion of the independence of those persons; promotion of diversity in the provision of social services; and affording choice and good practice in the provision of social services is to be identified, promulgated and promoted.[9] NCS cover services for adults; children and young people; everybody; and independent healthcare standards[10] and were created in an attempt to ensure that every individual in Scotland, irrespective of where they lived, would receive the same (high) quality of care, with six central principles of:

- Dignity;
- Privacy;
- Choice;
- Safety;
- Realising Potential;
- Equality and Diversity.

Each standard explains what can be expected for any given care service, written from the perspective of the care user.

In its recent response to the Inquiry Report of the Health and Sport Committee into the Regulation of Care for Older People (Health & Sport Committee, 2011) and the Scottish Government's own response to that report (Scottish Government, 2012e), SHRC welcomed the Committee's recommendation that a review of the NCS should embed equality and human rights for service users (SHRC, 2012b). However, SHRC also notes that whilst the NCS are underpinned by the human rights principles of: dignity; privacy; choice; safety; realising potential; and equality & diversity, a shared understanding of what this means in practice cannot be assumed and must be fostered through collaborative engagement in the issues (SHRC, 2012b).

SHRC believes that in order to apply the NCS in practice, in a way which squares the rights of the individual and is person centred, requires a thorough understanding of the human rights framework. SHRC will therefore continue to encourage the Care Inspectorate and others in the sector to develop their understanding of human rights standards as they apply in care settings (SHRC, 2012b).

In an effort to improve the way in which the NHS and Local Authorities work together and in partnership with the third and independent sectors, in May 2012, the Scottish Government launched a consultation on a set of proposals to change the way in which adult health and social care services are currently planned and delivered.[11] The aim of these proposals is to work towards providing a *"seamless experience* *from the perspective of the patient, service user or carer" (Scottish Government, 2012b).* In response to this consultation, SHRC has raised a number of key points. First, SHRC has asked that the Scottish Government to build human rights into the nationally agreed outcomes and outcome indicators or measurements that are to be established. Moreover, while the draft health and social care integration outcomes outlined in the consultation proposals both align and reference human rights, SHRC note that the full range of rights protection is not explicitly included in the seven outcomes and that there are significant gaps which should be addressed. SHRC also highlight that a human rights foundation ought to be explicit to the professional and workforce development that will be required to lead to the necessary cultural change to put the proposals into practice. In other words, in relation to joint strategic commissioning a shift to an outcome-based approach is required (SHRC, 2012c).

SHRC also raised three further points for the Scottish Government to consider regarding the integration of health and social care. First, there is a need for appropriate protection and regulatory measures, including of the home care sector and of those providing services directly to the service user. Second, the physical and psychological wellbeing of carers must also be considered where there is an increased reliance on their services without appropriate support and respite (see the final section of this theme for more discussion on carers). Finally, the proposals anticipate that:

> *"A more integrated approach to sharing information across services and local systems within appropriate boundaries… will be required to enable and evidence improvement" (SHRC, 2012c).*

Therefore, the Scottish Government must take on board the fact that privacy concerns which engage Article 8 of the ECHR may also be raised here and should be given further consideration (SHRC, 2012c).

Quality of care

The 2010 Scottish care homes census revealed that a total of 1,375 care homes provided care to 36,359 long stay residents as of 31 March 2010, 44 per cent of whom had diagnosed dementia.[12] As of 31 July 2011 there were 16,171 children in Scotland who were looked after, the highest number since 1981. The proportion of those children in residential care has, however, declined over the last four decades with corresponding increases in particular amongst foster carers, prospective adopters and other community placements (Scottish Government, 2012a).

In Scotland, the policy of free personal and nursing care is supported through *Better Health, Better Care: Action Plan* (Scottish Government, 2007). In particular, there is support for community care, where individuals are supported and cared for at home, if possible, in order to maintain their independence. There are also particular aims to support carers, including the provision of respite, and also to improve care home quality. A significant shift in the balance of care towards increased provision of care at home had occurred before the introduction of free personal care, and has continuing since.

Research has highlighted widespread misunderstandings of free personal care in Scotland concluding in 2007 that there was a gap in information and data available as to costs (Bowes and Bell, 2007) and in 2010 that there remains limited understanding of the policy amongst clients, carers and the media, where there is a common misconception that all social care for older people in Scotland is free (Bell, 2010). The research also highlighted the difficulties local authorities face in calculating the costs of free personal care and that there was unanticipated demand for free personal care. It has also been suggested that the provision of free personal care to over 65s only, may be open to challenge on age discrimination grounds (Bell, 2010).

A recent survey commissioned by the Scottish Government[13] found that a larger percentage of people felt that the care needs of older people are not currently being met (48 per cent compared to 36 per cent who felt those needs were being met). Nevertheless over three quarters (77 per cent) felt that care should continue to be provided in a similar way as at present with a majority (63 per cent) supporting the current system for funding care (Ipsos MORI, 2011). Moreover, in the future, the majority (68 per cent) believed that care should be paid for, as at present, from a mixture of general taxation and personal contribution. Even among those who oppose the current system for funding care, 45 per cent believed that care should be funded as it is at present, suggesting that, while they do not support the current system, they do not favour the possible two alternatives. Almost half (47 per cent) of people who oppose the current system believed that care for all older people should be paid for from general taxation.

The provision of free personal care policy has been challenged by some due to the increasing costs which have risen from £133m in 2003-4 to £342m in 2010-11, a rise of 150 per cent (Inclusion Scotland, 2012).[14] The amount of money spent by councils on free personal and nursing care to self-funding residents in care homes has increased from £86m to £108m, an increase of 25 per cent (Peterkin, 2011) and the number receiving free personal care at home has also increased by 42 per cent over the same period, from 32,870 in 2003-04 to 46,720 in 2010-11 (Inclusion Scotland, 2012)

A great deal of attention was paid in the research reviewed to the quality of care services, including those for children and young people, older people, and people with disabilities. Human rights based interventions too have been delivered in recent years, including the *Care about Rights?*[15] capacity building programme developed and delivered by SHRC. *Care about Rights?* is a programme of training and awareness raising which, at the time of writing, has reached over one thousand social care workers and managers across Scotland. It was designed to highlight the practical applications of human rights in the care sector for older people. It aims to demystify human rights to make it easier for care managers and staff to make decisions about care and to design policies for care that are well informed and grounded in the duties to respect, protect and fulfil human rights. An independent evaluation demonstrates tangible benefits for improving person centred and rights respecting care as well as in increasing awareness of human rights and in improving person centred care.[16]

As that training explains a wide range of human rights are engaged in the delivery of care services. Among these are absolute rights such as the right to life and the right to freedom from torture, inhuman or degrading treatment or punishment. Each of these includes positive obligations relevant in health policy and practice to prevent, protect and remedy. For example obligations related to the right to life (Article 2, ECHR) include: A positive obligation on the State to do *"all that could have been required of it to prevent the applicant's life from being avoidably put at risk"*[17] and in some cases an investigation or other effective remedy to ensure that cause of death can be determined, lessons learned and where civil or criminal negligence is an issue, those responsible made accountable.[18]

While this includes an element of individual accountability where appropriate its purpose is constructive accountability to learn lessons and improve standards in the future. Although the application of these principles in case law has tended to be limited to situations of detention, they may be relevant in care settings, particularly given that definitions of detention can be taken to include situations of de facto detention (such as where entry requires a door code which a resident with dementia may not remember). They have also at times been extended to hospital settings, the rationale for which would apply equally in care settings. As the ECtHR has stated:

> *"More general considerations also call for a prompt examination of cases concerning death in a hospital setting. Knowledge of the facts and of possible errors committed in the course of medical care are essential to enable the institutions concerned and medical staff to remedy the potential deficiencies and prevent similar errors. The prompt examination of such cases is therefore important for the safety of users of all health services".*[19]

Similar obligations exist in relation to the prohibition of torture, inhuman or degrading treatment or punishment (Article 3, ECHR). That right would be relevant to severe instances of abuse or neglect[20] where for example an individual is left in degrading conditions. For example the UK was found in violation of this Article where an individual who was four limbs deficient was left in a situation in which she:

> *"[was] dangerously cold, risks developing bed sores because her bed [was] too hard or unreachable, and [was] unable to go to the toilet or keep clean without the greatest of difficulty".*[21]

Qualified rights, such as the right to respect for private and family life, home and correspondence (Article 8, ECHR), are also relevant in social care policy and practice. That right has a very broad definition and includes the right to a home life, family life, physical and mental integrity, quality of life, well-being, autonomy, legal capacity and right to participate in decision-making. As a qualified right any limitation should have a basis in law, pursue a legitimate aim or goal and be proportionate, i.e. the least restriction which is capable of achieving the legitimate aim.

As outlined in the Care about Rights? Training materials: *"Article 8 relates to the following main interests:*

- **Privacy** – this is defined broadly and relates to all aspects of privacy both in and outside of an individual's private home
- **Family life** – this covers all close and personal ties of a family kind - not only those of a blood or formalised nature
- **Physical, psychological and moral well-being** – this covers the right to wellbeing through retaining autonomy, choice and dignity. It requires that there is access to information and participation in decisions that affect an individual's life

- **Home** – this is not about a right to a house but rather a right to respect for the home life of an individual
- **Correspondence** – this covers all forms of communication with others such as phone calls, letters, emails etc.” [22]

In relation to care of children the rights in the UN Convention on the Rights of the Child (CRC) should also be borne in mind. Among relevant rights are:

- the general principle that the best interests of the child must be a primary consideration in all actions concerning the child (Article 3, CRC);
- the right of the child, as far as possible, to know and be cared for by his or her parents (Article 7, CRC);
- the right to preserve family relations without unlawful interference (Article 8, CRC);
- the right of the child not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child (Article 9, CRC);
- the right of the child to participate in decisions, their views being given due weight according to age and maturity (Article 12, CRC);
- the right to privacy, family and correspondence (Article 16,CRC);
- the right to protection from “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse” (Article 19, CRC);
- the duty to ensure that the best interests of the child is the paramount consideration in a system of adoption (Article 21, CRC);
- the right to freedom from inhuman or degrading treatment or punishment (Article 37, CRC).

The UN Convention on the Rights of Persons with Disabilities (CRPD) spells out what should be done to break down the barriers which people with long term physical, mental, intellectual or sensory impairments may face in realising their human rights. As such the CRPD is relevant to people in care that, for example, have a visual or hearing impairment, or those who have dementia. Among relevant rights in the CRPD are:

- the right of disabled people to make their own decisions in all areas of life, on the same basis as other people and there are duties to provide the support people need to exercise that capacity. Decisions should only be made on behalf of people with disabilities where necessary, and with appropriate safeguards (Article 12, CRPD);
- the right to live independently and be included in the community (for example the right to choose where they live and who they live with and not to be unlawfully forced into a particular living arrangement) (Article 19, CRPD); and
- the right to be as mobile as possible (Article 20, CRPD).

Internationally, initiatives have begun which may lead to the development of a Convention on the rights of older people. SHRC’s Legal Officer Kavita Chetty has been involved in these initiatives, sharing experience gained from SHRC’s *Care about Rights?* training and capacity building programme and supporting understanding of the relevance of existing international human rights law, identifying any gaps for the rights of older people.[23]

Procurement of Care Services

In Scotland we have many contracted out and privatised public services such as social care, housing, prison services, and utilities. All of these types of services can have an impact on the delivery of human rights protections. The State has a 'duty to protect' against human rights abuses and the State's role as an economic actor is a key, but under used, leverage point in promoting corporate human rights awareness and preventing abuse. Public procurement and the contractual relationship between the state and private entities is one clear way in which businesses can be better held to account for their human rights responsibilities. One example is the growing concern around the commissioning and procurement of social care services.

In its response to draft Guidance on Social Care Procurement produced by the Scottish Procurement Directorate Joint Improvement Team, SHRC noted three potential problems with the proposed methods of social care commissioning (SHRC, 2010). The first was the lack of consultation and participation with service users for whom re-tendering can cause uncertainty about the future of their service with an impact for the service user and family of disruption, stress and anxiety. The second concern related to the quality of care, as re-tendering can cause the breakdown of cooperative relations and partnerships and there may be a lack of staffing continuity as re-tendering upon expiry of contacts may provide a disincentive to providers to invest and develop their workforce. Third, the quality of care may also be driven down by re-tendering as competitive tendering can lead to deterioration in service quality as a result of downward pressure on pay and conditions of staff (SHRC, 2010).

The Scottish Government Guidance on Social Care Procurement was published in April 2010 (Scottish Government and COSLA, 2010) and SHRC was pleased that human rights are referenced throughout. SHRC believes that this Guidance has opened the door to human rights being incorporated into: the service specifications; the selection and award criteria; and contractual clauses. In this way it is a progressive piece of guidance highlighting both the relevance and the way in which human rights can be integrated and become part of the fabric of the commissioning, procurement and delivery of these services (SHRC, 2012d).

In August 2012 the Scottish Government called for all those working within procurement across Scotland to consider current proposals for procurement reform, as the government hope to increase the impact of public procurement on apprenticeships and getting unemployed people back into work (Scottish Government, 2012c). SHRC will submit a response to this consultation in due course, once again outlining the positive benefits of placing human rights at the heart of procurement.

Older people

There has been growing press attention in recent years to the issue of abuse of the elderly within care settings.[24] Between 2004 and 2009 the Care Commission (now Care Inspectorate) recorded 1,529 specific complaints of abuse and neglect against adult care homes, 57 per cent of which were upheld or partially upheld (Adams, 2009). In June 2011, Elsie Inglis Nursing Home in Abbeyhill was closed down following police investigations into the deaths of two residents (BBC News, 2011b).[25]

Research in 2007 also showed that three per cent of people[26] aged 66 and over living in private households (including sheltered housing) in Scotland reported that they had experienced mistreatment involving a family member, friend, or care worker (Biggs et al., 2007, O'Keeffe et al., 2007). The predominant type of mistreatment reported was neglect, followed by financial abuse, psychological and physical abuse and finally sexual abuse (Biggs et al., 2007, O'Keeffe et al., 2007). Other research has revealed often unacceptable standards in the provision of care to older people in their own homes in the UK, most commonly in the form of neglect (EHRC, 2011, Triggle, 2012, Triggle, 2011, Age Scotland, 2012, STV News, 2009).

Some concern was also raised by participants in this scoping project about the lack of dignity often felt by those in receipt of health and social care services as well as the low status, pay and training of people who work in the care sector. As one participant noted:

> *Carers, whether they are employed or informal actually have the poorest paid jobs and often non-qualified. Scotland as a whole is becoming an older population and there is going to become a requirement for more care, care providers etc. and it's ok for us to say that [here] we are going to have X population over 60, over 70, over 80 and so on, but [here] it is an expensive place to live, how are you going to attract a younger population into this city to undertake such a low paid job?*
>
> **Rosie, Representative of an ethnic minority society and a volunteer interpreter**

Another participant who was training to be a social worker noted that during a placement in a care home for older people he had witnessed substandard care:

> *I was recently on a placement in an old folk's home here and what I saw shocked me. Where I worked the routine was get up in the morning, have a shower or whatever and then they just get put in rows in front a TV that is really far away where no one can really see it...lots of them hadn't been out of the building in a long time. One guy I spoke to hadn't been out of the building in 3 years, he hadn't even been in the garden or anything like that, no one had taken him out...because it was still under staffed and you would have a whole floor to look after with maybe 12 people and you would be on your own ...it's not really ideal because you would be a male working and half the people you would be helping would be female and you would be expected to clean and wash them and help them on the toilet and this would be really degrading for the women...you don't have time to sit down and talk because you are rushed off your feet all the time, and then when you do try to talk to them the nurses or managers are like, what are you doing you should be cleaning up or something like that.*
>
> **Eric, Trainee social worker (and care home agency worker) with experience in residential care of older people**

Concern has also been raised about the lack of sensitivity to the care needs (and cultural needs) of different minority ethnic groups (MacDonald, 2004, Netto, 2001, Bowes and MacDonald, 2000), although little recent research was identified which explored the needs of minority ethnic groups in care facilities (or in receipt of care services). A participant in SHRC's national consultation (SHRC, 2009) noted a specific example of a member of a minority ethnic group living in a care home who required medical treatment. This person did not speak English and it took ten days for an interpreter to become available to accompany them to see a doctor. A number of participants in this scoping project highlighted this lack of knowledge and suggested that future research should focus on the experience of such groups in care homes.

In 2011, the Mental Welfare Commission, the Scottish Human Rights Commission and the Care Inspectorate (then SCISWIS) were made aware of the use of closed circuit television (CCTV) in a very small number of individuals' rooms in a registered care facility. A joint statement was issued giving guidance on the use of CCTV in care homes and emphasised that this must be the exception, rather than blanket use, and that it must only be used where it can be justified as the least intrusive means of keeping a person safe (SCSWIS et al., 2011). As the guidance stated,

> *"The disproportionate use of CCTV is an intrusion into an individual's privacy and dignity (Article 8 of the European Convention for Human Rights). The presence of a camera, whether or not it is activated, may be deemed a threat to individual privacy. Any such interference must be proportionate, for a legitimate aim and lawful. In particular, it must only be undertaken where there is the proper legal authorisation in place, e.g. authorisation via a guardianship order with the specific power to use CCTV in respect of the individual's welfare" (SCSWIS et al., 2011)*

Participants in this scoping project also raised concern about a particular proposal in one local authority to place CCTV cameras into the homes of those who are elderly or disabled and more vulnerable to accidents. The idea was to use new technology to provide an extra layer of care to those living in sheltered housing units.

In relation to care home environments, previous research has shown that care home environments are generally good and getting better but more needs to be done to make them appropriate to those with dementia (Care Commission and Mental Welfare Commission for Scotland, 2009). Areas of good practice, have been highlighted, such as evidence of creative thinking to maximise quality of life such as planned outings with a resident to lunchtime music concerts and to a cafe he used to frequent (Care Commission and Mental Welfare Commission for Scotland, 2009). Similarly, in 2010 MWC found many good practices in residential care for people with learning disabilities, including homely, pleasant bedrooms where residents could spend time with their personal belongings, music and TV and with some choice in decor and furnishings. There was also a good level of understanding about the need to encourage and support residents to stay in touch with family and friends[27] (Mental Welfare Commission for Scotland, 2010). [NB. efforts to enhance independent living and reduce institutionalisation of people with learning disabilities are discussed below].

However, in their joint investigation into the treatment of people with dementia in care homes MWC and the Care Commission also found areas of concern. These included a lack of activities and stimulation in a care home setting, with 50 per cent of residents never going out of the home. This was alongside a finding that insufficient priority was given to understanding the person as an individual, their life history, likes and dislikes. The report recommended that residents' finances should be used creatively to maximise their quality of life. (Care Commission and Mental

Welfare Commission for Scotland, 2009). [NB. The issues of consent to treatment, which was also raised, is considered in the section on mental health care and treatment in the thematic section on health]

In June 2012, attention was drawn to the large turnover of carers for those receiving care at home and the impact that can have on the dignity, privacy and distress of older people. Following the death of her husband Jeanette Maitland recorded that she and her husband had received over 100 different carers in their home in the year before his death.[28] This approach to care delivery raises questions of the proportionality of the impact on the right to respect for private and family life, under Article 8 of the ECHR.

A number of participants in this scoping project also reported that those in receipt of care services at home often found the constant change of care staff very distressing and believed that more consistency in who provided care could dramatically improve how services were received:

> *… it's the dignity aspect as well, dignity for older people. I was doing cleaning for an elderly brother and sister. He was about 90 and she was 87 and I felt when the lassies were coming in to shower them and stuff… different girls all the times… she'd ask me to tell them to go she wasn't feeling well… It wasn't the fact that it was a young girl so much, but it was the constant changing of carers all the time, and different days and different times, there was no set pattern, she was terrified by this point. She needed some kind of continuity of care and she wasn't getting it. It was good that they were coming to her house, but too many people, maybe if it was just 2 people and they spoke to her first rather than just going straight into showering them…*
> **Flora, Domestic cleaning worker and member of a women's support group**

Participants in this scoping project also reported practices which may leave those in receipt of care services at risk of abuse. In one area of provision, older people who were receiving a large number of services from a range of different individuals were reported to be required to leave their doors unlocked when they couldn't afford sufficient keys to be cut. Overall, however, participants in this scoping project did feel that people should be able to remain in housing, living independently and out of institutional care (if this was their choice), and most participants felt that the provision of free social care was something that the Scottish Government should be proud that it provides. However, there was some scepticism about the Scottish Government's ability to continue to provide, for free, the level of care required for an ageing population. As one participant noted:

> *They say people want to live at home, well, yes and no, people want to live at home when there is a good level of care and where their dignity is intact, but that is not always happening. In the current economic climate and with an aging population how realistic is this policy?*
> **Arnold, Area senior citizens chairman**

Participants in this scoping project also spoke to positive experiences in care settings in Scotland. Some participants in this scoping project discussed the various ways in which they felt that it was the quality of the staff and the way they approached their work that made the difference:

> *This is the best care home in Scotland! I think we are really lucky here……when you look at the news and see what has happened elsewhere, we really are amazingly lucky here. The staff are delightful and varied, the standards of food and cleanliness are very high… One thing is very simple, the staff here are careful and helpful. It makes a huge difference. I was speaking to someone who came here from another home and she said the staff there were rough and unforthcoming, they did their job but that was it. Our staff are really friendly and nice which I think is very important, quite apart for the standards like cleanliness and laundry and food and things as well… aye it is the staff that really make the difference.*
> **Audrey, Resident in a privately run care home for older people**

Staff at the home referred to by Audrey had reinforced how important they felt that it was to treat all residents with respect and ensure that they lived dignified lives. The manager had undergone *Care about Rights?* training which she felt had been valuable in reinforcing good working practice.[29]

A number of participants in receipt of care services in rural areas talked of a service of befriending social support that had helped them to feel less socially isolated. This service would match up friends and befrienders in some cases as pen pals and in other cases via telephone calls. Most found this service a lifeline:

> *Fred ...rings me every Thursday and we get on like a house on fire, we have got an awful lot in common so at the minute I have asked the manager about another day for him to call me during the week. I know he is busy, but the depression in here every day, it really gets to you. The only ones you have to talk to are the carers really, that's the only way to find out what is happening in the outside world. The contact with Fred has made a lot of difference.*
> **Eric, Recipient of a rural befriending service and a person living with multiple physical disabilities**
>
> *My befriender is, I think, a big civil servant and he tells me about his hobby of model railways. He's got a caravan and he uses half of it for his modern railways and his wife gets the other half for her craft stuff. When they went on their holiday it was as if I was taken with them, they gave me photographs of every place they'd been over the 3 weeks and I got a window on the world with them.*
> **Timothy, Recipient of a rural befriending service and a resident in a privately run care home (mental health care needs)**

Children and young people

Particular issues emerged from the scoping project review regarding 'through-care', the process by which the local authority prepares young people for life after care services for children.[30]

Scotland's Commissioner for Children and Young People (SCCYP) has called for further work to be done in relation to young people leaving care after they turn sixteen. Social workers are required to assist and encourage young people to remain in care until they are eighteen, but there is evidence that this does not always happen in practice (Scotland's Commissioner for Children and Young People, 2008). SCCYP calls for changes to the law to prevent councils placing young people in homeless hostels and bed and breakfast establishments, and ensuring that there are options open to young people if their first steps towards independence don't work out. Recommendations include semi-independent living units to be put in place as a stepping stone (Scotland's Commissioner for Children and Young People, 2008).

Research has revealed that compared with other young people, those leaving care are more likely to have poor educational outcomes and access to further and higher education and to experience low paid employment or unemployment (Reed in Partnership, 2011). They are also more likely to experience poor health, particularly poor mental health, misuse alcohol and drugs and have difficulties with relationships with family and friends (Elsley et al., 2007). Research has also repeatedly shown a strong relationship between living in care and teenage pregnancy. A quarter of care leavers have had a child by the age of 16, with almost half of care leavers becoming mothers within the first two years months of leaving care (SCIE, 2005).

Research has also highlighted areas for improvement for those children and young people living in care. For example McGuinness reports that incorrect understandings of health and safety regulations often curtail the enjoyment of outdoor play by children in care, which can cause undue stigmatisation (McGuinness et al., 2007). Similarly, research by SCCYP has also revealed difficulties faced by young people with mobility difficulties in accessing outings and activities as a result of inadequate and inconsistent moving and handling procedures (Paton, 2008). Young people have reported feeling embarrassed, humiliated, undignified and excluded because of moving and handling difficulties (Paton, 2008).

The Scottish Government's Action Plan to implement recommendations made by the UN Committee on the Rights of the Child, *Do the Right Thing* (Donnelly, 2009), included commitments to improving outcomes for looked after children, including challenging stigma/ reducing discrimination and improving support for care leavers. The coalition of children's rights organisations in Scotland, Together,[31] has also recommended that the Scottish Government should put in place a framework to enable the on-going monitoring and evaluation of policies affecting looked-after children, in order to see what impact they have in reducing the number of children coming into care, and improving the lives of looked after children(Together, 2011, Together, 2012). Moreover, they have called on the Scottish Government to provide better support to improve contact proceedings for children separated from their family. Participants in this scoping project who lived within some of Scotland's island communities were particularly critical of the lack of contact with family when living in care, as children were often placed in care on different islands from family due to a lack of available care services.

Autism

It has been estimated that approximately one per cent of the UK population (i.e. 50,000 people in Scotland) have some form of autism spectrum disorder (ASD)[32] (Mullen, 2010). Of those the National Autistic Society reports that only 7,500 are known to local authorities.[33] The results of a survey published in 2011 by the National Autistic Society in Scotland found that:

> *"• A third of people have waited more than two years for a diagnosis of autism, and some people told NAS that they have been waiting more than ten years to get a diagnosis.*

> *• 52 [per cent] of adults with autism are financially dependent on their families*
> *• Although many adults with the condition want to work, only 13 [per cent] are in full-time employment*
> *• Over half of adults with autism have experienced bullying or harassment since they were 18*
> *• In the UK, 27 [per cent] of children with autism have been excluded from school. Children with autism are three times more likely to have mental health problems than other children."* [34]

Participants in an event on the UN Disability Convention organised by the EHRC and SHRC were also critical of the lack of suitable support services provided locally and of facilities for those over 16 with ASD (EHRC and SHRC, 2011). Similarly participants in this scoping project who were parents of autistic children were generally critical of a lack of a whole range of services for their children including out of hours specialist care, support workers in school to facilitate engagement with mainstream school and dieticians.[35] For example, one mother spoke of her struggle to access a dietician for her autistic child:

> *My main issue is support for people with additional needs and their families. For example, there is one dietician in the whole of the Highlands for children that is specialised in autism and I have been waiting months and months and months, I couldn't even tell you how long and I couldn't even tell you when I am going to get to see him, it is ridiculous.*
> **Freya, Mother of a child with autism and a member of women's support group.**

Participants in this scoping project, particularly those who had or knew of children with these conditions also felt that society in general was not well educated about ASD:

> *Society does not know enough. People know more, a bit more now about learning difficulties and disabilities now, and we know more about physical disabilities, but with autism, ADHD, Asperger's, hidden disabilities people often question, hmm have they really got it…?*
> **Lina, Mother of a child with autism and a member of women's support group.**

Deficiencies in the provision for care for people with ASD have also been the subject of a report by the MWC (Mental Welfare Commission for Scotland, 2009). The report on the care and treatment of Mr Q[36] a 35 year old man with Asperger's Syndrome who ordinarily lived with his mother but from July 2004 until April 2008 was detained in hospital. Concerns were raised about the care received whilst in hospital and ultimately the MWC investigation found:

> *"little evidence that the clinical team actively considered how they could provide a therapeutic environment and a care regime suited to someone with ASD" a "lack of coherent joint planning which kept Mr Q in hospital for almost 4 years with little obvious benefit to him" (Mental Welfare Commission for Scotland, 2009).*

The report makes a range of recommendations in respect of the care of people with Asperger's in non-specialist wards (Mental Welfare Commission for Scotland, 2009).

Civil society organisations and movements of affected people have also raised questions, including with SHRC, over the effectiveness of both hospital detention and the use of antipsychotic drugs (Autism Rights, 2009, Autism Rights, 2007, Tomsho, 2009). In further testimony to SHRC, affected people have also raised concerns regarding, among other things: difficulties in the establishing a diagnosis of ASD; general treatment of those with ASD including what they believe to be an over reliance on (inappropriate) medication; a lack of appropriate facilities close to home, particularly for those who are transitioning from children's services and for those with severe ASD conditions; the facilities and management of some services (lack of grounds access, disproportionate use of seclusion with a lack of stimulation) and inappropriate informal detention.[37]

Following the failure of the Autism Bill, introduced into the Scottish Parliament by Hugh O'Donnell MSP,[38] in November 2011, the Scottish Government published the Scottish Strategy for Autism to be delivered in partnership with the Convention of Scottish Local Authorities (COSLA) (Scottish Government, 2011). It was developed as the result of collaboration with the ASD Reference Group of users, carers, local and central government representatives, voluntary organisations, NHS staff and academics (Scottish Government, 2010b) which has been reconvened and expanded to support delivery of the strategy. The strategy is underpinned by the values of dignity, privacy, choice, safety, realising potential and equality and diversity. Each of these has human rights counterparts. The promotion and protection of human dignity is the fundamental rationale for human rights. Human rights both protect people from treatment which infringes dignity (or inhuman or degrading treatment or punishment, Article 3, ECHR); and promote the right of individuals to live with dignity, including autonomy, and protections of the requirements of a life with dignity such as the right to education and to the highest attainable standard of physical and mental health. Similarly privacy is upheld in human rights in the right to respect for private and family life (Article 8, ECHR) (Scottish Government, 2011).

The strategy includes a range of goals, indicators and recommendations which are indirectly linked to human rights and a small number which include explicit links. Among those that have indirect links are those related to access to services; the participation of people with autism and their carers in developing local strategies, policies and plans; Amongst other elements of the strategy which reference human rights explicitly are a recognition that:

> *"Local authorities and health boards would benefit from having a central resource which showed how legislation, guidelines and statutory obligations fit together. This would give greater clarity and would encourage agencies to work better together to meet their statutory obligations. It would include reminding them of their obligations under the equality and human rights legislation to ensure equality of access to mainstream public services" (Scottish Government, 2011).*

Independent living of disabled people

The right to live independently as part of a community is guaranteed in Article 19 of the UN Disability Convention. Article 19 provides that disabled people have the right to choose how to live their lives, to be fully included and to participate in society. It focuses in particular on the choice of where and with whom to live and being able to live in a community in a manner that supports and fosters inclusion and participation. That in turn requires that there should be access to support services and that general services should be equally available and accessible for disabled people. As the Council of Europe Commissioner for Human Rights, in his recommendation on the right to independent living summarised:

> *"The overarching objective of Article 19 of CRPD is full inclusion and participation in society. Its three key elements are: choice; individualised supports that promote inclusion and prevent isolation; and making services for the general public accessible to people with disabilities" (Council of Europe Commissioner for Human Rights, 2012).*

A study supported by the European Commission (European Foundation Centre, 2010) has specified that the obligations under Article 19 should include, among other things, taking effective measures to make a variety of living arrangements available to disabled people. Under the Convention those should include a range of options for residential, shared sheltered accommodation, and for providing the same choices as are available to others (UN CRPD, 2009). Amongst other things Article 19 has been said to establish a strong presumption against long-term institutional care, or in favour of de-institutionalisation (European Foundation Centre, 2010). As the Council of Europe Commissioner has further expressed:

> *"This right is violated when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support; when support is provided in a way that takes away people's control from their own lives; when support is altogether withheld, thus confining a person to the margins of the family or society; or when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition" (UN CRPD, 2009).*

The Council of Europe Commissioner for Human Rights makes 15 recommendations as to how States should act to comply with Article 19, including:

> *"…adopt a no-admissions policy to prevent new placements of persons with disabilities in institutional settings...set deinstitutionalisation as a goal and develop a transition plan for phasing out institutional options and replacing them with community-based services, with measurable targets, clear timetables and strategies to monitor progress" (UN CRPD, 2009).*

Other obligations include identifying and addressing barriers that disabled people face in realising the right to independent living, undertaking housing audits, involving disabled people in all efforts to advance independent living and assessing the availability of the support services, access to in-home support and safeguards against isolation (Joint Committee for Human Rights, 2011).

The right to independent living does not exist as a specific right in UK law, and whilst it is protected and promoted by a range of rights, the UK Parliament's Joint Committee on Human Rights has stated that this is not sufficient. The Joint Committee criticised the UK Government first, for viewing the UN Convention on the Rights of Persons with Disabilities as 'soft' rather than 'hard' law (and for conveying that opinion to the general public) and second, for failing thus far to fulfil their obligations under the UNCRPD (Joint Committee on Human Rights, 2012).

In Scotland, the Scottish Government, the Convention of Scottish Local Authorities (COSLA) and the Independent Living in Scotland (ILiS) Steering Group signed a Shared Vision for Independent Living in Scotland in 2009 (Reid Howie Associates, 2007).[39] In 2010 NHS Scotland became the fourth signatory. That Vision defines independent living is linked to choice, control, freedom and dignity, that it covers every aspect of an individual's life – at work, at home and in the community, and established a model of 'co-production' with each signatory an equal partner in an Independent Living Core Reference Group (CRG). The CRG operates across government and is co-chaired by the Scottish Government Director for Strategy and Performance and the Convener of the ILiS Steering Group. There remains no overarching strategy on independent living in Scotland, although there have been repeated calls for one.[40]

The Independent Living Fund supports people to live independently in Scotland by supplementing funding from the local authority for people with high support needs. The funding is flexible and portable and could include support in the home, in the community, at college or university, to gain the skills needed to participate in work, or merely to carry out the role of a parent. The Independent Living Fund[41] income to Scotland was £59.6 million (Independent Living in Scotland, 2010). The fund was unique in terms of its flexibility, portability and efficiency, with 97p for every pound (£) going direct to the service user. In January 2010 it was announced that the Independent Living Fund would be closed to new applications and in December 2010 it was announced that it would be phased out completely by 2015 (BBC News, 2010). ILiS expressed concern about the impact of this decision, which was reportedly made without consultation or an equality impact assessment. It also noted concern that these decisions are an obstacle to the Government's expressed commitment to approaching community care with the aims of achieving inclusivity, dignity, equality, fairness, empowerment, enablement, choice, control and freedom (Independent Living in Scotland, 2010).

Participants involved in EHRC/SHRC events to promote the UN Disability Convention have consistently identified independent living as an "*overarching priority".*[42] In doing so participants have referenced the broad understanding of independent living promoted by the Independent Living in Scotland project:[43]

> *"[It involves] disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life" (Independent Living in Scotland, 2010).*

De-institutionalisation

In 2000 the Scottish Executive published a report entitled *The same as you?* (Scottish Executive, 2000) which included 29 recommendations aimed at improving services so that:

> *"people with learning disabilities had the right to be included in, and contribute to, society, to have a voice, and to have access, with their families, to support to live the life of their choosing" (Scottish Executive, 2000).*

Key among its recommendations was a move away from long-term institutional care for people with learning disabilities. By 2007, of 120,000 adults with learning disabilities 388[44] remained within in-patient services (Perera et al., 2009). In a 2008 report, the Mental Welfare Commission for Scotland considered that:

> *"there is a large group of people who could move out of hospital if appropriate support was available. There is a clear need for health boards and local authorities to agree local strategies to develop the services necessary to enable people to move on from hospital" (Mental Welfare Commission for Scotland, 2008).*

Nevertheless the evaluation of *The same as you?* in 2012 found:

> *"Since 2000, more than 1,000 people have moved out of hospital into homes in the community. The closure of all the long-stay learning disability hospitals is a key achievement from The same as you? The overwhelming majority of adults with learning disabilities now live in the community. More people have experience of supported living, although some people are still in inappropriate placements and there is a wide variation in packages of support" (Scottish Government, 2012d).*

The evaluation also, however, pointed to a need for:

> *"a much greater emphasis on support that builds people's capacity to lead independent, healthy lives" (Scottish Government, 2012d).*

Similarly, evidence gathered indicates that there is not currently enough short break provision for people with learning disabilities and their carers (Trew, 2010).

In addition it has been estimated that around 869 people with learning disabilities, many of whom are under 55, were resident in care homes for older people in 2009 (Learning Disability Alliance Scotland, 2010). Many of these residents were found to be around twenty years younger than the other residents. The report raised concerns that staff in these homes lacked specialised training in supporting people with learning disabilities. Often the activities on offer in a care home environment were found to be infrequent and not appropriate for people with learning disabilities. In a specialised care home for people with learning disabilities, the average number of residents is nine, as opposed to forty in a residential care home for older people. The report calls on local authorities to ensure that every person with learning disability living in a residential care home has a person centred plan to support them to lead a full life and for a review of the practice of such placements (Learning Disability Alliance Scotland, 2010).

Self-Directed Support

The goals of maximising independence in the community are acknowledged in the principles which underpin key legislation in Scotland. In December 2010 the Scottish Government published a draft Bill on self-directed support. The Social Care (Self Directed Support) (Scotland) Bill aims to empower people to take as much control as they want in the process of obtaining good quality care and support and is premised on principles of increased choice, control, independence and dignity. The goal is to move away from 'gift and service based models' towards person centred support and better outcomes for people. Direct Payments, which have until now been optional for some service users, will become the norm in future. The Bill's proposals include:

- introducing the term self-directed support into statute and providing for general principles on user choice and control,
- placing a duty on local authorities to provide people with a range of options so that the citizen can decide how much choice and control they want e.g. the

individual receives the payment and chooses what type of service they wish, but employment and other issues continue to be dealt with by the local authority,

- powers for local authorities to provide support to carers along with a duty on the local authority to empower the carer to direct their support,
- encouraging and underpinning self-directed support in relation to packages involving joint social and health care funding,
- consolidating and modernising current statute on direct payments (Campbell, 2011).

SHRC has broadly welcomed the Bill, welcoming the introduction of self-directed support as a positive step towards increasing independent living but reiterated that the intentions of the Bill do not overshadow the obligations of the state to respect, protect and fulfil human rights – including through adequate support and safeguards to ensure care and support is provided at a level which does not fall below minimum thresholds. SHRC recommended that the Bill include a duty on local authorities to have regard to the right to independent living, with appropriate assistance and support to make informed choices. SHRC also recommended that clauses in the Bill which provided for assistance in decision making to those who may *"benefit"* from it due to *"mental disorder"* or *"difficulties in communicating due to physical disability"* should be clearly linked to legal protections for legal capacity in decision making. Further, concern was expressed at the proposed blanket exclusions from eligibility for self-directed support and direct payments of categories of persons such as those subject to compulsion orders, emergency or short term detention certificates, supervision and treatment orders (SHRC, 2011).

A small number of participants were in receipt of care services at home and were in the process of moving onto a system of Self Directed Payments. All were optimistic about the potential that this system offered their ability to participate in decisions about their own care and to have a level of control over what they personally prioritised in their care package. For example, Eric is in the process of starting his self-directed payments. On the morning of this interview he had just found out that he had been allocated a social worker to help him put everything in place. Even before he had received confirmation of this he had already been discussing the prospect of self-directed care with two women who currently provided care for him and he had already devised a rota in his mind of how his care could work. He described how the self-directed payments would increase his autonomy by allowing him to "*stay in control of the purse strings"* and prioritise what care he wants and when he wants it:

> *I will be able to decide what I want to get and how long I get it for rather than them saying what I can have. Just now they can say my first call is at half 9 in the morning and my last call is at 5.45 at night and that's it until the next morning – they class that as a bed call, but nobody really wants to go to bed at 6.15 or 6.30 at night. And nobody else comes to make sure that you've got your medication or that you are ok until the next morning. So with the direct payment I can get someone in at 9pm at night just for 15 minutes to make sure I am alright, that I've taken my pills on that occasion and they can then get me into bed and then once I'm there I am fine until the next morning.*
> **Eric, Recipient of a rural befriending service and a person living with multiple physical disabilities**

Eric also spoke of the value he found in the personalised approach to care:

> *If I hadn't the girls coming in now I don't know where I'd be to be honest. I really have become very much dependant on them and I do enjoy my chats with them, it breaks my day...The contact and the time to talk to me are just as important as the things that need done...For me, losing your independence, I might as well be dead. So my carers are so important to me… they do it because they care, it's not pity or feeling sorry for you, they just care.*

The close linkages between a personalisation and a human rights based approach has been outlined in a recent policy paper published by The Centre for Welfare Reform (Chetty et al., 2012). This paper argues that Scotland's current health and social care system lacks any explicit guiding principles and is now in need of development in order to develop a modern, coherent values base to fit with new structures and expectations with an emphasis on human rights at the very heart of a personalised system of care and support.

Chetty et al. (2012) argues that human rights-based and person-centred approaches share the same starting point: the personal experiences of the individual and they share the same end goal: empowering individuals to fulfil their potential by giving them the authority, capacities, capabilities and access needed to change their own lives, improve their own communities and influence their own futures. Although the origins of the concept of personalisation goes back to the activist history of the disability movement and other marginalised groups, the more recent articulation of the idea as a public policy places relatively little emphasis on human rights. Despite concern to improve whole systems of public services, social and health care by placing the individual at their centre, this is being done without an attendant or consequent stress on the human rights of that individual.

There is indeed, significant scope for the Convention rights in the Human Rights Act to be better understood and applied more consistently to advance the personalisation agenda. To date, however, Chetty et al. (2010) note that the framework of rights has not been central to the development of personalisation as a key driver of public policy. As a consequence, much of the new autonomy proposed through personalisation has the feel of a set of '*privileges'* that can be variously afforded, denied or withdrawn by professionals acting on behalf of the state through the apparatus of local government. In other words the service that is received, feel as if it is driven not by what people need but by what the system can deliver.

Some research has also revealed concerns that the personalisation process has coincided with significant budgetary cuts.[45] According to Learning Disability Alliance Scotland there will be 1,800 people with learning disabilities on individual budgets with other client groups to follow over the course of the next two years. In Glasgow (one of the Scottish Government's three test sites for Self-Directed Payments), the Council's budget options report a £13 million saving over the next two years leading to anecdotal concerns amongst carers such as the impact of potential savings to care packages leading to carers having to make difficult choices regarding quality and quantity of care, short timescales and the bureaucracy of managing direct payments.[46]

A number of participants in this scoping project who were working within the health and social sectors were concerned that the climate of shrinking resources may impact on the personalisation of care:

> *I think trying to tailor a service to the individual is a nice idea, but how realistic is that? And how much money does it cost in this day and age with all the public spending being cut? We have to look over the next 20 years and beyond…Especially with the turnover of staff in the caring sector as well, are you going to cater for different cultures and beliefs that might be very different?*
> **Larissa, Civil servant and 3rd sector volunteer worker.**

Chetty et al. (2012) do argue that the Self-Directed Support Strategy together with the associated legislation in progress, create a solid platform to build on and should be implemented locally in such a way that the human rights principles that lie at its core. They note a word of caution, however, that there is a risk with Self-Directed Support legislation that unless deliberate steps are taken to address the human rights deficits and power imbalances, there will be too narrow a focus on the system and process changes required to implement the mechanisms of self-directed support; and existing managerial and clinical models of service delivery will persist.

A human rights based approach is helpful in addressing these issues, providing a framework of responsibilities which places the individual's choice and control at the centre of decision making while balancing this with responsibilities to safeguard the individual from harm, the broader public interest and the rights of others.

Service delivery

In March 2010 the Scottish Government estimated that 66,222 disabled people access home care and support in Scotland.[47] In 2009 ILiS expressed the view that:

> *"the provision of health and social care services does not always meet disabled people's needs, with inequalities evident in health outcomes" (Independent Living in Scotland, 2009).*

Their report noted amongst other things variations in standards of care and a lack of provision for specific groups of disabled people (Independent Living in Scotland, 2009).

The impact of funding cuts has also been linked to reduced quality of care. A recent survey into the funding decisions by 111 UK[48] councils and health and social care trusts revealed that 82 per cent of the sample had cut the visiting times for some clients receiving home care and the average visit had fallen from 48 minutes to 38 minutes. The visits affected include those for safety checks, social contact, help with washing, bathing and continence, managing finances, cleaning, shopping and laundry (Dunning, 2011).

The impact of tendering processes has also raised concern in research. For example Ross reports that retendering of respite services in the Highlands and Islands may result in a reduction in the number of hours of respite care available to carers by over 60 per cent in some areas (Ross, 2011).

ILiS has promoted the importance of portability of care to realising the right to independent living and the right to mobility under the UN Disability Convention. They argue that if the government understands the importance of inclusion and family life, and the essential contribution to care in the community made by the 660,000 informal carers in Scotland, then it is essential that people are able to move to be closer to friends and family and it is counterproductive to present barriers to this (Independent Living in Scotland, 2008). At present the Ordinary Residence rule determines which local authority area pays for an individual's community care package (Scottish Government, 2010a). COSLA itself has also recognised that:

> *"the level at which people begin to pay charges [for non-residential social care services] varies significantly across local authorities" (COSLA, 2010).*

As a result COSLA has developed some guidance which attempts to develop a framework within which local authorities make decisions on charging for non-residential social care services (COSLA, 2010).

Disabled people have expressed concern to SHRC and EHRC and to the ILiS project about problems in the portability of care which include variations in eligibility criteria between local authorities, requirements for different assessments in different areas meaning a lack of assurance on similar level of provision and variation in charging for community care meaning that it may be financially unviable for disabled people to move. It has been suggested that this results in barriers to disabled people accessing work and higher education in other local authorities, as well as generally exercising their right to freedom of movement and choice of residence within the country. The Independent Living Movement in Scotland has called for a human rights based approach to portability of care that identifies and then removes this barrier to their right to independent living, and that this should be progressed together with disabled people (Independent Living in Scotland, 2009).

Gaps in service provision which were identified by disabled people during participation events on the UN Disability Convention included a lack of accessible transport, particularly in rural areas (EHRC and SHRC, 2011). This confirmed previous research which found that disabled people remain 50 per cent less likely to make any kind of journey than non-disabled people (Scottish Executive, 2006).

Self determination

Issues of self-determination, autonomy and participation permeate a human rights analysis and have been highlighted in many thematic sections (see e.g. sections on participation and informed consent in thematic section 2 on Health; and family life of people with learning disabilities and forced marriage under private and family life). This section will consider issues of legal capacity, including guardianships, as well as end of life decisions.

Legal capacity

As noted above, the right to respect for private and family life includes a right to self-determination, autonomy and decision making. It is closely linked to the right to legal capacity (Article 12 of the UN Disability Convention) and is indispensable to the right to independent living, amongst others.

In Scotland the Adults with Incapacity (Scotland) Act 2000 (AWIA) was considered the first law of the Scottish Parliament which tackled a significant policy area.[49] It addressed a global trend towards a more individualised, functional or "*tailor made*" approach to assessing whether an individual has capacity to make decisions and its passage followed:

> *"unprecedented openness, involvement of affected citizens, and responsiveness to their views" (Ward, 2008).*

AWIA itself is explicitly built on human rights foundations, taking account of Council of Europe Regulations on the subject. For example it provides that any intervention in the affairs of an adult should be the:

> *"…least restrictive option in relation to the freedom of the adult, consistent with the purpose of the intervention."*[50]

This seeks to apply the test of proportionality in an interference with the right to private and family life. Subsequently AWIA has been considered a model of best practice and taken into account in similar legislative processes across the world and in deliberations at the European Court of Human Rights (ECtHR).

The Human Rights Act requires that all laws should be read through the lens of the ECHR rights, and the ECHR is a "*living instrument*". Since the entry into force of AWIA in 2002 understanding of the requirements of the ECHR in this area has developed significantly. The UN Convention on the Rights of Persons with Disabilities (adopted in 2006 and binding on the UK since 2009) is increasingly influencing how the ECtHR is addressing legal capacity.

Recent decisions of the ECtHR in this area have held that:

- *"…the existence of a mental disorder, even a serious one cannot be the sole reason to justify full incapacitation." Any interference with legal capacity – such as a finding of full or partial incapacity or a guardianship order – is an interference with the right to private and family life and must be based on law, pursue a legitimate aim and be a proportionate means of achieving that aim.*[51]
- *Individuals have a right to a fair hearing (including right to participate in decisions and of access to a court to challenge decisions) in relation to a determination of their legal capacity.*[52]
- *Blanket restrictions on a group of people to exercise capacity in a certain area simply due to the existence of a partial guardianship is disproportionate.*[53]

A series of reports suggest practice in Scotland remains uneven[54] and a study from 2005 suggested that there may be low levels of awareness of the AWIA among health workers (Ramsey, 2005). Following a consideration of practice and the developing approach of the ECtHR the Public Guardian concluded in 2011 that:

> *"…several aspects of the current system e.g. use of interim guardians, use of indefinite orders and the granting of unnecessary welfare powers arguably breach human rights legislation."*

In response the Public Guardian has recommended a more explicitly human rights based approach (Office of the Public Guardian, 2011).

The Mental Health (Care and Treatment) (Scotland) Act 2003 also introduces a number of steps to advance legal capacity, including advance statements,[55] and a right to access independent advocacy.[56] A key review of the legislation, however, pointed to low take up of such measures and recommended greater publicity be given to them.[57] Likewise concerns have been raised regarding the electoral registration of older people, including those with dementia, living in care homes. In response SHRC launched a campaign, together with the Electoral Commission, and the Care Commission (now Social Care and Social Work Improvement Scotland). The commissions issued a leaflet stating:

> *"It is important that you do not make an assumption about an individual's capacity to vote or apply a "one size fits all" approach to all residents. Each individual must be assessed on a case by case basis at the time of their decision making and in relation to voting. The fact that an individual has dementia, for example, does not necessarily mean that they will lack capacity to vote on 5 May 2011" (SHRC et al., 2011).*

Following the Scottish Local Authority elections in May 2012, Highland Council has produced a review of the turn out and an evaluation of the impact of methods used to encourage voting. The campaign by SHRC, the Electoral Commission, and the Care Commission was noted as one of the methods by which older voters were informed about how to vote and the evaluation further noted that there would be value in reviewing the processes (in health and social care or with care homes) by which the Electoral Registration Office are informed of a change in circumstances when an older person moves into residential care, in order that they are notified to update their electoral registration (especially for postal voting which was found to be the most utilised method of voting in the Highlands) (Highland Council Chief Executive, 2012).

A further area of controversy in the exercise of autonomy is in relation to end of life decisions. In the case of *Pretty v. United Kingdom*[58] the ECtHR considered the balance to be drawn between the right to autonomy under Article 8 of the ECHR and the right to life in Article 2 of the ECHR. It found that the right to life does not imply a right to die, nor does the right to autonomy entail a right to *"decide when or how to die."*[59] In the case of R *(on the application of Purdy) v Director of Public Prosecutions*[60] the House of Lords required the Director of Public Prosecutions in England to clarify his position on the prosecution of those who assist suicide. He subsequently issued guidelines in February 2010 which clarified the factors to be taken into account in determining whether a prosecution for assisting suicide is in the public interest (Director of Public Prosecutions, 2010). More recent cases, including the case of Tony Nicklinson who died in August 2012, have sought, as yet unsuccessfully, to challenge the ban on voluntary euthanasia.[61]

In Scotland the Lord Advocate made it clear that the Director of Public Prosecutions; Guidelines on Assisted Suicide would not apply and that *"any change in the current law related to homicide is properly a matter for the Scottish Parliament" (The Journal, 2009)*. In response SHRC considered that:

> *"It is possible to imagine a Purdy-style challenge being brought in Scotland since at present there is no way of knowing how the prosecuting authorities might respond to a relative who assisted the death of an individual. The concern is the lack of sufficient foreseeability. In order to be sufficiently foreseeable, there must be a sufficient degree of clarity in the law and its application. The law should be formulated with sufficient precision to enable the individual, if need be with appropriate advice, to regulate her conduct"(SHRC, 2012a) .*[62]

It called on the Lord Advocate to issue interim guidance to further clarify the position in Scotland in relation to prosecutions for assisted suicide.

Margo MacDonald MSP has made two as yet unsuccessful attempts to introduce legislation on the matter.[63] Informed by papers prepared by Dr. Mary Ford and Professor Sheila McLean, SHRC's submission on the End of Life (Assistance) (Scotland) Bill 2010 noted that there was no consensus on the subject of assisted dying at European level and that the ECtHR has not taken the view that the Convention requires either the prohibition or the permission of assisted suicide. It noted that a clear policy as to when it would, and would not, be appropriate to prosecute individuals who help others to die is indispensable.

The Commission also noted concerns that a disproportionate focus on the exercise of autonomy in conceptualising human dignity may discriminate against people with disabilities. As Baroness Campbell of Surbiton (a member of the UK Parliament's Joint Committee on Human Rights and former Commissioner with the EHRC) has highlighted the risk associated with such decisions related to the lives of people with disabilities:

> *"Society today still discriminates against people with severe disabilities and illnesses. Our lives are seen by many as inferior to those of non-disabled people. Against this background, there is the inherent danger that actions to withdraw treatment and legalized assisted dying will place disabled people are greater risk" (Clements and Read, 2008).*

Carers' rights

SHRC's Chair, Professor Alan Miller, has described Scotland's unpaid carers as *"heroes, who save the public purse many millions of pounds".*[64] While in doing so they support the realisation of the rights of those they care for to human dignity, as outlined above, unpaid caring also has an impact on the rights of carers themselves. Amongst other rights engaged are the right to respect for private and family life (Article 8, ECHR) as unpaid caring responsibilities have an impact on the autonomy, physical and mental integrity, quality of life, and well-being of carers. Their rights to an adequate standard of living (Article 11, International Covenant on Economic, Social and Cultural Rights, ICESCR) and the right to work (Article 6, ICESCR) of unpaid carers are also engaged.[65]

There are estimated to be approximately 660,000 of people in Scotland (one in eight of the population) who provide unpaid care today.[66] It is estimated that this represents a saving to the public purse of between £7.6-10.6 billion a year (Carers UK, 2011, Payne, 2011) equivalent to the majority of the total NHS budget for Scotland. Indeed there are more carers in Scotland than the entire health and social care workforce added together. Of the total 660,000 carers, more than 115,000 provide in excess of 50 hours a week of informal care. Moreover, more than 100,000 of Scotland's unpaid carers are young carers aged from three to eighteen and a fifth of those carers provide from 29-30 hours a week of care (Carers UK, 2011).

Unpaid carers are:

> *"Individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system" (Care 21, 2006).*

Within legislation an unpaid carer is:

> *"someone who provides substantial amounts of care on a regular basis for either an adult or a child, where that adult or child receives, or is eligible to receive, support services under the Social Work (Scotland) Act 1968[67] or the Children's (Scotland) Act 1995".[68]*

These two pieces of legislation and the Community Care and Health (Scotland) Act 2002, provide all carers with the statutory right to request an independent carer's assessment of their ability to care for another individual/s, on top of any assessment that the person needing care receives (Stewart and Patterson, 2010). Young carers have also been further recognised as having specific support needs because they are children and young people first, carers second (COSLA and Scottish Government, 2010b).

In 2011 Carers UK undertook research into the impact of informal, unpaid caring. The results showed amongst other things that, of informal carers surveyed in Scotland:

- 82 per cent felt their health had been affected by fuel poverty
- 79 per cent had experienced mental ill-health as a result of caring
- 74 per cent had to cut back on leisure activities
- 47 per cent had to cut back essentials (like food and heating)
- 45 per cent were currently in debt as a result of caring
- 45 per cent felt that money worries was impacting on their health
- 32 per cent were using an overdraft to cope
- 29 per cent were using credit cards to cope
- 12 per cent had taking out a loan to cope.

(Carers UK, 2011)

Policy and strategy responses

Recognition of the needs of carers has developed over time. In 1999 the then Scottish Executive launched the Strategy for Carers in Scotland (Scottish Executive, 1999) which aimed to improve the information available to carers; introduce new legislation; ensure the existence of national standards on short breaks; and to improve local services available to carers. This was followed in 2005 by the Care 21 Report on The Future of unpaid care in Scotland (Care 21, 2006) which provided 22 recommendations for improving the lived experience of carers in Scotland. Priority action areas included: understanding and providing for the needs of young carers; carer training; improving respite care and improving the health of carers.

In 2010 the Scottish Government launched *Caring Together* (COSLA and Scottish Government, 2010a) which set out ten key actions to support carers in recognition of the vital role they play as partners in delivering care. Amongst the actions were:

- the development of a Carers' Rights Charter;[69]
- measures to improve the uptake of carers assessments and support plans;
- ensuring carer representation on Community Health Partnerships;
- the investment of £281,000 in carer training; and promotion of carer friendly employment practices.

The report acknowledged the need to take positive steps to identify and support 'hidden' carers in the minority ethnic communities (including Scottish Gypsy/ Travellers) and in rural areas. Further funding was allocated to support young carers alongside the publication of *Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015* (COSLA and Scottish Government, 2010b).[70]

One of the manifesto commitments of the SNP Government elected in 2011, in support of carers in Scotland, was the development of a Carers Parliament which would meet annually to allow carers of all ages to raise any issues that impacted on their lives with Scottish Government Ministers and MSPs in order to facilitate a more direct channel for the voices of carers to be heard in the decision-making process. This Carers Parliament met for first time on 1 October 2012 (Carers Scotland, 2012) with a focus for the day on how all partners can find a way to deliver better services and support to carers and the people that they care for. At this inaugural Parliament, Alex Neil MSP, Cabinet Secretary for Health and Wellbeing, emphasised the need for the Scottish Parliament to "*listen to carers*". One session focused in particular on carers' rights, concluding that there already exists a great deal of legislation and policy that could help carers, in other words the structures and some of the processes already exist. However, not enough carers are aware of their rights as carers or their human rights, to be able to access those rights. For example, whilst every carer is eligible to a carer's assessment a,[71] this is not on the whole happening in practice. Only when carers ask for an assessment is this happening.

Improving the support provided to unpaid carers in Scotland is included in a number of Single Outcome Agreements between the Scottish Government and local authorities. It is further supported by a specific Community Care Outcome which aimed to ensure that user and carer satisfaction and support were embedded at the heart of community support services (Stewart and Patterson, 2010).

Particular groups of carers

In 2012, following an awareness-raising afternoon with Gypsy/Travellers, where the Scottish Parliament Equal opportunities Committee heard evidence from Gypsy/Travellers with caring responsibilities about the many difficulties they face, the Committee launched an inquiry into Gypsy/ Travellers and Care.[72] Evidence sessions began on March 27 2012 with oral evidence from a range of third sector organisations with a broad experience of carers' issues including evidence from MECOPP [Minority Ethnic Carers of Older People Project] who began a new project in May 2011 working with Gypsy/ Travellers in three areas of Scotland to better understand the views and experiences of Gypsy/ Travellers carers (MECOPP, 2012).

Initial findings from the MECOPP Gypsy/ Travellers carers project (MECOPP, 2012) highlighted that most Gypsy/ Travellers did not view themselves as carers or use the term 'carer', they were fulfilling 'family duty', something which participants involved in this research considered to be part of their everyday family responsibilities. The research also highlighted that many Gypsy/ Travellers carers encountered community and service isolation, struggled to trust official services and would often travel considerable distances to use a trusted service rather than face rejection from a local one (MECOPP, 2012). Participants involved in this scoping project talked about their distrust of anyone in a position of authority, with many feeling unable to make use of certain services or to admit to those services that they were a Traveller for fear of receiving a poorer service:

> *Are you going to be treated worse because you have said that you are a Gypsy/ Traveller, are you going to be treated better or worse? You've got this attitude because you have been harassed all your life, 'collar and ties', ken? Services with authority, I have never trusted and I still don't trust.*
> **Mary, Scottish Gypsy/Traveller.**

The MECOPP (2012) research also found that most Gypsy/ Travellers carers are not making regular use (if at all) of social care services (voluntary or statutory) and most are unaware of (and in turn not in receipt of) Carers Allowance. Finally, the general health of most Gypsy/ Travellers carers was found to be visibly poor, with nearly all reporting mental health problems as a direct result of their caring responsibilities (MECOPP, 2012).

The Equal opportunities Committee published its report on its inquiry into Gypsy/ Travellers and Care on the 24th of September 2012, concluding that:

> *"…in spite of the various reports and initiatives of recent decades, little has changed for Gypsy/Travellers. Our finding has been guided by evidence outlining repeated failures: recommendations have not been implemented, initiatives have often been small-scale or short-term and, according to Gypsy/Travellers themselves, they have been fighting the same battles for decades. Access to health and social care alongside other public services must be universal; it is clear that this is not the experience of Gypsy/Travellers living in Scotland today. We look to the Scottish Government to take the strategic lead, with speed and commitment, in making real, significant changes to the lives of Gypsy/Travellers and, by taking positive action to improve their future, to begin to earn Gypsy/Travellers' trust".*[73]

Previous research (Netto, 2001)(now over ten years old) also revealed some evidence that many minority ethnic carers face additional hurdles in accessing information regarding their rights and in accessing culturally appropriate care. This scoping project highlighted that an attitude that ethnic minorities *"look after their own"* continues to prevail despite evidence to the contrary (Netto, 2001). The research suggests that little is known about the extent of unmet need amongst ethnic minority communities (Netto, 2001). The research made a number of recommendations including better involvement of ethnic minority communities in shaping local authorities' approaches as well as in the planning and development of health and care services. Finally the research suggested that targets should be set for the employment of members of ethnic minorities at all levels in the community care sphere (Netto, 2001). In a more recent study, Richardson and Laird (2012) suggest that in order to enhance carer-involvement in care-related research a number of factors are relevant, including being involved in initiatives that have a practical beneficial outcome for carers or those they look after. Further, the authors propose that for Black and minority ethnic carers, interpreter and translation resources, gender sensitivity and flexibility around their involvement are key factors to encourage participation (Richardson and Laird, 2012).

Other research has suggested that carers in rural areas face cumulative pressures of increased travel, higher travel costs, fewer support services and more problems accessing employment suitably flexible to work around caring responsibilities. The research recommended that the Scottish Government abolish the ‘one size fits all’ approach to carer’s allowance and increase investment in rural initiatives (Carers UK, 2008).

A number of participants in this scoping project provided unpaid informal care for their families. Many noted their daily struggle to combine financial survival and caring responsibilities, with many unable to work due to their caring duties, making it difficult to lift themselves out of poverty. One woman spoke of the difficult situation her husband was in as a result of having to stop work to care for her:

> *My husband can’t actually get a decent payment; he gets £14 a week on income support, after working for 38 years in one job. He gets £14 a week on income support because I get incapacity, now where is the sense in that? Where are his rights to having some money? There are times he needs to get out and have a break, maybe to visit his friend who lives on the other side of the island. I have to pay for that, I have to give him money because he gets £14 a week.*
> **Cherie, Participant at a rural mental health association**

Finally, as noted above, approximately 100,000 of Scotland’s unpaid carers are young carers. The caring responsibilities undertaken by these children and young people means that most struggle to have what others would consider to be a ‘regular’ childhood, seeing friends, going out to the cinema, playing sports, and so on. A recent survey comparing the activities and experiences of young carers (aged 10-19) with young people who participated in Schools Adolescent Lifestyle and Substance Use Survey (SALSUS) revealed that only 11 per cent of young carers see friends every day and 9 per cent had the opportunity to visit the homes of friends less than weekly or never. Of those young carers who responded to the survey, 60 per cent cared for more than 20 hours a week, whilst 20 per cent cared more than 50 hours a week. The majority cared for their mother.[74]

Louise Morgan, Young Carers Services Development Manager for The Princess Royal Trust for Carers in Scotland, responded to this research noting:

> *“Young carers take on a hugely important role in our society, providing care for their families and saving the country millions of pounds. The least we can do is recognise this by doing our best to support them and prevent them taking on too much responsibility at a very early stage in their lives”.* [75]

Moving Forward

This section, alongside the other thematic sections and the overarching contextual chapter, has highlighted gaps, and inconsistencies, as well as good practices in the realisation of human rights in practice in Scotland. Addressing these shortfalls should be a concern of all bodies with responsibilities, including Government, local authorities, other public authorities and private providers of public services.

Identifying the shared framework of responsibilities and agreeing steps to address gaps requires an inclusive process of engagement. It should result in clarity on what action such bodies will take and when concrete improvements can be expected – it should result in specific, measurable, achievable, relevant and time-bound objectives. An independent system for monitoring progress should also be agreed. In short, the report supports the conclusion that Scotland needs a National Action Plan for Human Rights. To develop this SHRC will host human rights InterActions involving a broad range of public and private bodies, civil society and individuals. These InterActions will follow a FAIR approach:

> **F***acts:* What are the key gaps and the good practices in the realisation of human rights in Scotland?
> **A***nalysis of rights at stake*: Which human rights are at stake? Is any restriction on the rights justified? Is the extent of realisation of the right reasonable?
> **I***dentify responsibilities*: What changes are necessary? Who has responsibilities for helping to make the necessary changes?
> **R***ecall and review progress*: Independent monitoring according to agreed indicators and periodic review of progress.

This process will allow for constructive dialogue between those with responsibilities and those whose rights are affected. Further, it will clarify the steps that are required to improve human rights practice in Scotland taking a pragmatic approach to understanding financial and other constraints. It is hoped that Scotland's National Action Plan for Human Rights will launch in summer 2013.
To inform the process of developing Scotland's National Action Plan for Human Rights responses are requested to the following questions:

> **1. Based on the evidence presented in this report, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?**
>
> **2. What specific and achievable actions do you consider would best address the concerns you identify in terms of question 1?**

Please use the form at the end of this section and send your responses to actionplan@scottishhumanrights.com or post it to us at Scottish Human Rights Commission, 4 Melville Street, Edinburgh, EH3 7NS

Table 1: Key Dates

Date	**Action**
May 2012	The UK Universal Periodic Review at the United Nations begins.
September 2012	The final report and recommendations of the UK's Universal Periodic Review is anticipated
October 2012	Publication of SHRC's Report and launch of a process of participation to shape Scotland's National Action Plan for Human Rights
December 2012	SHRC hosts a National InterAction to address the findings of the scoping exercise and facilitate negotiation of commitments to address them
Aiming for Spring 2013	A draft of Scotland's first National Action Plan for Human Rights is published for comment
Aiming for Summer 2013	Scotland's National Action Plan for Human Rights will be launched
June 2014	UK's progress on Universal Periodic Review recommendations is considered in a mid-point review. Progress on Scotland's National Action Plan for Human Rights to feed into this process.

PARTICIPATION FORM
SCOTLAND’S NATIONAL ACTION PLAN FOR HUMAN RIGHTS

Views are sought from all individuals and organisations who have experience or expertise which can help to shape Scotland’s National Action Plan for Human Rights.

The Scottish Human Rights Commission will be collecting and analysing all responses receive before the **29 March 2013**. Early responses are encouraged.

Unless respondents request that their views remain confidential or anonymous all responses will appear online with the organisation or individual named as the respondent. Contact details for the respondent will not appear online.

- Please tick this box if you do not wish your response to appear online:
- Please tick this box if you are happy for your response to appear online but not your name or organisation’s name to appear:
- Please tick this box if you would prefer we did not link to your website:

Name: ____
Organisation: (where appropriate) _______________________
Website: ____
Email address: ______________________________________
Contact telephone number: ___________________________

This form can be returned by post to: Dr Alison Hosie, Scottish Human Rights Commission, 4 Melville Street, Edinburgh, EH3 7NS, or sent as an electronic or scanned document to actionplan@scottishhumanrights.com

You can also fill out this form online at www.scottishhumanrights.com/actionplan

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1. Based on the evidence presented in the report *Getting it right? Human rights in Scotland*, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland’s National Action Plan for Human Rights?

2. What specific and achievable actions do you consider would best address the concerns you identify in your response to question 1?

Thank you for sharing you experience or expertise and helping to shape Scotland's National Action Plan for Human Rights.

Contact point: Dr Alison Hosie / actionplan@scottishhumanrights.com / 0131 240 2989 / www.scottishhumanrights.com/actionplan / @scothumanrights

Bibliography

ADAMS, L. 2009. Scotland's Secret Scandal - abuse of the elderly. *The Herald*, 12th October 2009.
AGE SCOTLAND 2012. At home with Scotland's older people: Facts and Figures 2011-12. Edinburgh: Age Scotland.
AUTISM RIGHTS. 2007. Incompetent, Abusive, or both? - Scottish Executive policy and legislation on Autistic Spectrum Disorder (ASD) - 'Autism Rights' Briefing Paper April 2007. Available: http://www.autismrights.org.uk/MainText.html [Accessed 27th March 2012].
AUTISM RIGHTS. 2009. Child and Adolescent Mental Health Services Inquiry, Evidence to the Scottish Parliament Health and Sport Committee. Available: http://www.scottish.parliament.uk/S3_HealthandSportCommittee/Inquiries/MH36.pdf [Accessed 21st October 2011].
BBC NEWS. 2010. Independent Living Fund to be shut down by 2015, http://www.bbc.co.uk/news/uk-11985568 *BBC News*, 13 December 2010.
BBC NEWS. 2011a. Government condemns shocking Winterbourne View abuse. *BBC News* [Online]. [Accessed 19th September 2012].
BBC NEWS. 2011b. Second death probed at Elsie Inglis nursing home. *BBC News* [Online]. [Accessed 19th September 2012].
BELL, D. 2010. The impact of devolution: long term care provision in the UK. York: Joseph Rowntree Foundation.
BIGGS, S., TINKER, A. & MCCREADIE, C. 2007. Elder Abuse. London: Comic Relief and the Department of Health
BOWES, A. & BELL, D. 2007. Free Personal Care for Older People in Scotland: Issues and Implications. *Social Policy and Society,* 6, 435-445.
BOWES, A. & MACDONALD, C., . 2000. Support for Majority and Minority Ethnic Groups at Home - Older People's Perspectives. *Social Work Research Findings.* Edinburgh: Scottish Executive Central Research Unit.
CAMPBELL, A. 2011. SPICe Briefing: Commission on the future delivery of public services Edinburgh: Scottish Parliament.
CARE 21 2006. The Future of Unpaid Care in Scotland: Headline Report and Recommendations and Appendices. Edinburgh: Scottish Executive.
CARE COMMISSION & MENTAL WELFARE COMMISSION FOR SCOTLAND 2009. Remember, I'm Still Me: Care Commission and Mental Welfare Commission joint report on the quality of care for people with dementia living in care homes in Scotland. Dundee & Edinburgh: Care Commission & Mental Welfare Commission.
CARERS SCOTLAND 2012. Your priorities for a Carers Parliament. Glasgow: Carers Scotland.
CARERS UK 2008. Carers in crisis: A survey of carers' finances in 2008. London: Carers UK.
CARERS UK. 2011. *Carers deserve a right to life outside caring* [Online]. Edinburgh: Carer Scotland. Available: http://www.carersuk.org/newsroom-scotland/item/2082-carers-deserve-a-right-to-life-outside-caring [Accessed 24th March 2012 2012].
CHETTY, K., DALRYMPLE, J. & SIMMONS, H. 2012. Personalisation and Human Rights: A Discussion Paper. Edinburgh: SHRC, Neighbourhood Networks, Alzheimer Scotland and The Centre for Welfare Reform.
CLEMENTS, L. & READ, J. 2008. Disabled People and the Right to Life, Luke Clements and Janet Read. , Abingdon, Routledge.

COSLA 2010. Charging Guidance for Non-residential Social Care Services: 2010 – 2011. Edinburgh: COSLA.
COSLA & SCOTTISH GOVERNMENT 2010a. Caring Together: The Carers Strategy for Scotland 2010 - 2015. COSLA & Scottish Government.
COSLA & SCOTTISH GOVERNMENT 2010b. Getting It Right For Young Carers: The Young Carers Strategy for Scotland: 2010 - 2015. COSLA & Scottish Government.
COUNCIL OF EUROPE COMMISSIONER FOR HUMAN RIGHTS 2012. THE RIGHT OF PEOPLE WITH DISABILITIES TO LIVE INDEPENDENTLY AND BE INCLUDED IN THE COMMUNITY, . Strasbourg: Council of Europe.
CRAIG, G. 2011. Mapping human rights organisations in Scotland. Durham: University of Durham, School of Applied Social Sciences.
DIRECTOR OF PUBLIC PROSECUTIONS 2010. Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, February 2010, http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html. Edinburgh: Director of Public Prosecutions.
DONNELLY, R. 2009. Do the Right Thing: A report for under 18s on Scottish Government priorities in response to the UK Concluding Observations 2008. The Scottish Government.
DRIVER, S., LAMB, M. & WILSON, C. 2010. Annotated Bibliography of Published and Grey Non-Legal Literature on Human Rights in Scotland since 2006. London: The Crucible Centre and Social Research Centre, ROEHAMPTON UNIVERSITY.
DUNNING, J. 2011. *Service users at risk as homecare cuts shorten visits* [Online]. Surrey: Community Care. Available: http://www.communitycare.co.uk/Articles/05/09/2011/117392/service-users-at-risk-as-home-care-cuts-shorten-visits.htm.
EHRC 2011. Close to home: An inquiry into older people and human rights in home care. London: EHRC.
EHRC & SHRC 2011. Being part of Scotland's story under the disability convention: The report of the joint Commissions' participation event with disabled people in Scotland about the United Nations Convention on the Rights of Persons with Disabilities. Glasgow: Equalities and Human Rights Commission and Scottish Human Rights Commission.
ELSLEY, S., BACKETT-MILBURN, K. & JAMIESON, L. 2007. Review of Research on Vulnerable Young People and Their Transitions to Independent Living. Centre For Research on Families and Relationships, The University of Edinburgh.
EUROPEAN FOUNDATION CENTRE 2010. Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities . Brussels: European Foundation Centre.
FLANIGAN, D. 2011. Mapping the Law of Scotland in Relation to Economic, Social & Cultural Rights. Glasgow: Scottish Human Rights Commission.
HEALTH & SPORT COMMITTEE 2011. Health & Sport Committee 3rd Report 2011 (Session 4) - Report on Inquiry into the Regulation of Care for Older People. Edinburgh: Scottish Parliament.
HIGHLAND COUNCIL CHIEF EXECUTIVE 2012. Highland Elections – Encouraging Participation and Increasing Turnout. Inverness: Highland Council.
INCLUSION SCOTLAND 2012. Working towards a society where disabled people are equal citizens. Glasgow: Inclusion Scotland.
INDEPENDENT LIVING IN SCOTLAND 2008. Policy Briefing 8: Portability of Care and Support. Glasgow: Independent Living in Scotland EHRC.

INDEPENDENT LIVING IN SCOTLAND 2009. Ready for Action: Key Issues and Disabled People's Priorities for Independent Living. Glasgow: Independent Living in Scotland EHRC.
INDEPENDENT LIVING IN SCOTLAND 2010. Policy Briefing 4: Independent Living Fund. Glasgow: Independent Living in Scotland EHRC.
IPSOS MORI 2011. Public Attitudes to the Future of Care Provision in Scotland. Edinburgh: Scottish Government Social Research.
JOINT COMMITTEE FOR HUMAN RIGHTS 2011. UNCORRECTED TRANSCRIPT OF ORAL EVIDENCE, IMPLEMENTATION OF THE RIGHT OF DISABLED PEOPLE TO INDEPENDENT LIVING, TUESDAY 14 JUNE 2011
MIKE SMITH, MONICA McWILLIAMS, BOB COLLINS and DUNCAN WILSON; DIANE MULLIGAN OBE, DAVID RUEBAIN, PAULINE THOMPSON OBE and KAREN ASHTON, HC 1074-ii, pp4-8. . London: Joint Committee for Human Rights.
JOINT COMMITTEE ON HUMAN RIGHTS 2012. Human Rights Joint Committee - Twenty-Third Report Implementation of the Right of Disabled People to Independent Living. London: UK Parliament.
LEARNING DISABILITY ALLIANCE SCOTLAND 2010. Stuck - 869 people with learning disabilities resident in care homes for older people in Scotland. Dalkeith: Learning Disability Alliance Scotland.
MACDONALD, C. 2004. Older People and Community Care in Scotland: A Review of Recent Research. Edinburgh: Scottish Executive.
MCGUINNESS, L., STEVENS, I. & MILLIGAN, I. 2007. Playing It Safe? A study of the regulation of outdoor play for children and young people in residential care. Scotland's Commissioner for Children and Young People.
MECOPP 2012. Hidden Carers, Unheard Voices: Informal caring within the Gypsy/ Traveller community in Scotland. Edinburgh: Minority Ethnic Carers of People Project.
MENTAL WELFARE COMMISSION FOR SCOTLAND 2007. Older and Wiser. Mental Welfare Commission for Scotland.
MENTAL WELFARE COMMISSION FOR SCOTLAND 2008. A Hospital or a Home? : Mental Welfare Commission for Scotland.
MENTAL WELFARE COMMISSION FOR SCOTLAND 2009. Summary of investigation into the care and treatment of Mr Q. Mental Welfare Commission for Scotland.
MENTAL WELFARE COMMISSION FOR SCOTLAND 2010. A home of my own: Report from our visits to people with learning disabilities who are living in care homes which are registered with the Care Commission as having more than 20 places June to September 2010. Edinburgh: Mental Welfare Commission for Scotland.
MULLEN, F. 2010. SPICe Briefing: Autism (Scotland) Bill Edinburgh: Scottish Parliament.
NETTO, G. 2001. "No one asked me before": Addressing the needs of black and minority ethnic carers in Edinburgh and the Lothians. Edinburgh Scottish Ethnic Minorities Research Unit
NORMAND, A. & WEBSTER, E. 2010. Mapping the Law of Scotland in relation to International Human Rights Treaties – Civil and Political Rights. Glasgow: University of Strathclyde.
O'KEEFFE, M., HILLS, A., DOYLE, M., MCCREADIE, C., SCHOLES, S., CONSTANTINE, R., TINKER, A., MANTHORPE, J., BIGGS, S. & ERENS, B. 2007.

UK Study of Abuse and Neglect of Older People: Prevalence Survey Report. National Centre for Social Research and King's College London.

OFFICE OF THE PUBLIC GUARDIAN 2011. Office of the Public Guardian (Scotland), Early Deliberation on Graded Guardianship, paper drafted by Sandra McDonald, Public Guardian, November 2011. London: Office of the Public Guardian.

PATON, L. 2008. Handle With Care: a report on the moving and handling of children and young people with disabilities. Scotland's Commissioner for Children and Young People.

PAYNE, J. 2011. SPICe Briefing: Adult Community Care- key issues. Edinburgh: Scottish Parliament.

PERERA, C., SIMPSON, N., DOUDS, F. & CAMPBELL, M. 2009. A survey of learning disability inpatient services in Scotland in 2007. *Journal of Intellectual Disabilities,* 13, 161-171.

PETERKIN, T. 2011. Call for rethink as cost of free personal care for elderly soars 139% in six years. *The Scotsman* 31st August 2011

RAMSEY, S. 2005. The Adults with Incapacity (Scotland) Act – Who Knows? Who Cares? . *Scottish Medical Journal,* 50, 20-23.

REED IN PARTNERSHIP 2011. From Care to Independence: Improving employment outcomes for care leavers. London: Reed in Partnership.

REID HOWIE ASSOCIATES 2007. Independent living in Scotland: a policy scoping study. Stratford upon Avon:: Disability Rights Commission.

RICHARDSON, E. & LAIRD, S. E. 2012. Involving carers from minority ethnic backgrounds in carer-led research. *Disability & Society.* Oxford: Routledge.

ROSS, D. 2011. Cuts to respite spark protest. *The Herald*, 25th August 2011.

SCIE 2005. SCIE research briefing 9: Preventing teenage pregnancy in looked after children London Social Care Institute for Excellence.

SCOTLAND'S COMMISSIONER FOR CHILDREN AND YOUNG PEOPLE 2008. Sweet 16? The Age of Leaving Care in Scotland. Scotland's Commissioner for Children and Young People.

SCOTTISH EXECUTIVE 1999. Strategy for Carers in Scotland. Edinburgh: Scottish Executive.

SCOTTISH EXECUTIVE 2000. The Same as You? A review of services for people with learning disabilities. Edinburgh: Scottish Executive.

SCOTTISH EXECUTIVE 2006. Improved Public Transport for Disabled People: Volume II - Annexes 1-3. Edinburgh: Scottish Executive.

SCOTTISH GOVERNMENT 2007. Better Health, Better Care: A discussion document. Edinburgh.

SCOTTISH GOVERNMENT 2009. Review of Mental Health Law Consultation Analysis. The Scottish Government.

SCOTTISH GOVERNMENT 2010a. Guidance on the recovery of expenditure on accommodation and services under section 86 of the Social Work Scotland Act 1968 – ordinary residence. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT 2010b. Towards an Autism Strategy for Scotland. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT 2011. The Scottish Strategy for Autism. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT 2012a. Children Looked After Statistics 2010-11. *Statistics Publication Notice: Health and Care Series.* Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT 2012b. Integration of Adult Health and Social Care in Scotland: Consultation on Proposals. Edinburgh: Scottish Government.
SCOTTISH GOVERNMENT 2012c. Procurement Reform Bill – Consultation. Edinburgh: Scottish Government.
SCOTTISH GOVERNMENT 2012d. The same as you? 2000-2012: Consultation Report. Edinburgh: Scottish Government.
SCOTTISH GOVERNMENT 2012e. Scottish Government.s response to the Health and Sport Committee 3rd Report 2011: Report on Inquiry into the Regulation of Care for Older People. Edinburgh: Scottish Government.
SCOTTISH GOVERNMENT & COSLA 2010. Procurement of care and support services. Edinburgh: Scottish Government.
SCSWIS, MENTAL WELFARE COMMISSION FOR SCOTLAND & SHRC 2011. Joint statement on the use of CCTV in care facilities. Edinburgh: SCSWIS, Mental Welfare Commission for Scotland, SHRC.
SHRC 2008. Scottish Human Rights Commission STRATEGIC PLAN 2008-2012. Glasgow: SHRC.
SHRC 2009. Building a Strategic Plan: Consultation Report. Glasgow: Scottish Human Rights Commission.
SHRC 2010. Submission to Scottish Procurement Directorate – Joint Improvement Team, Social Care Procurement Scotland Guidance. Glasgow: Scottish Human Rights Commission.
SHRC 2011. Response to Consultation on the draft Social Care (Self Directed Support) (Scotland) Bill. Edinburgh: Scottish Human Rights Commission.
SHRC 2012a. End of Life Assistance (Scotland) Bill, http://archive.scottish.parliament.uk/s3/committees/endLifeAsstBill/evidence/ELA474.pdf Edinburgh: Scottish Human Rights Commission.
SHRC 2012b. Response to Call for Evidence issued by the Health and Sport Committee: Inquiry into Regulation of Care for Older People. Edinburgh: Scottish Human Rights Commission.
SHRC 2012c. Response to Consultation on proposals on the Integration of Adult Health and Social Care in Scotland. Edinburgh: Scottish Human Rights Commission.
SHRC 2012d. Scottish Human Rights Commission Submission to Scottish Government consultation on Legal Challenges to Decisions by Public Authorities Under the Public Participation Directive 2003/35/EC. Edinburgh: Scottish Human Rights Commission.
SHRC, ELECTORAL COMMISSION & CARE COMMISSION 2011. Supporting Residents to Vote on 5 May 2011, http://www.scottishhumanrights.com/application/resources/documents/election2011infoforcarehomes.pdf. Edinburgh: SHRC, Electoral Commission & Care Commission.
SMITH, R., TAIT, L., BALES, K., MCCONNELL, L. & RABAN-WILLIAMS, R. 2010. Mapping the Law of Scotland in Relation to International Human Rights Treaties: CAT & CPT. Newcastle: Northumbria Law School.
STEWART, F. & PATTERSON, E. 2010. Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland. Edinburgh: Scottish Government Social Research.
STV NEWS. 2009. Shocking figures show rise in complaints for care of the elderly. 12 October 2009.
THE JOURNAL. 2009. Guidance on assisted suicide won't apply in Scotland: Angiolini, *http://www.journalonline.co.uk/News/1007039.aspx* [Online]. Edinburgh: The Law Society of Scotland. [Accessed 10th September 2012 2012].

TOGETHER 2011. State of Children’s Rights in Scotland, 2011. Edinburgh: Together - Scottish Alliance for Children’s Rights.
TOGETHER 2012. State of Children’s Rights in Scotland, 2012. Edinburgh: Together - Scottish Alliance for Children’s Rights.
TOMSHO, R. 2009. Study Confirms Antipsychotics Pose Heart Risk. *The Wall Street Journal* [Online]. Available: http://online.wsj.com/article/SB123195561087782025.html?mod=googlenews_wsj#articleTabs%3Darticle [Accessed 27th March 2012].
TREW, C. 2010. The same as you? Evidence Scoping Exercise. Glasgow: Scottish Consortium for Learning Disabilities.
TRIGGLE, N. 2011. Basic home care help ’breaching human rights’. *BBC News Health*, 23rd November 2011.
TRIGGLE, N. 2012. Home care for elderly branded ’shocking and disgraceful’. *BBC News Health*, 16th March 2012.
UN CRPD 2009. Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities, . Geneva: UN Committee on the Rights of Persons with Disabilities.
WARD, A. D. 2008. *Adults with Incapacity Legislation,* Edinburgh, Greens Essential Legislation.

Appendix 1: Prioritisation criteria to select Phase 2 issues for further study

Occurrence: Number of Phase 1 sources commenting on a particular issue in relation to the Right being examined.

Devolved competence: Allows scoring according to whether an issue is reserved and wholly beyond the powers of devolved government, partly within the powers of devolved government, or fully within the powers of devolved government to address.

Gravity: Score reflects the nature of the rights at stake:

Category 1.Qualified & limited Rights, Economic, Social & Cultural Rights, the Right to an Effective Remedy, Non-discrimination in the Exercise of Rights

Category 2.The Right to Life, Retrospective Criminal Law and Absolute Rights (Right to be Free from Torture& Inhumane and Degrading Treatment and Prohibition of Slavery).

Imprint: Score reflects the extent to which the issues raised in a particular category would affect a large number of people

Vulnerability/ Marginalisation: Score reflects the extent to which the issues raised affect vulnerable or marginalised groups/communities.

Added value: Scores reflect whether the issue contributes to the human rights culture of Scotland without duplicating research work already being done by other bodies (or within the clear remit of other organisations)?

Opportunity: Scores reflect whether the issue creates/ensures the establishment of positive, supportive interaction and understanding between the SHRC and institutions or individuals where previously this did not exist?

Endnotes

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1 Further details on the methods and methodology of this scoping project can be found in the main report which can be accessed at: http://www.scottishhumanrights.com/actionplan

2 The data sources collated and analysed in the first phase included:
An annotated bibliography of published and “grey” social research. DRIVER, S., LAMB, M. & WILSON, C. 2010. Annotated Bibliography of Published and Grey Non-Legal Literature on Human Rights in Scotland since 2006. London: The Crucible Centre and Social Research Centre, ROEHAMPTON UNIVERSITY. See also Hosie & Lamb (2013 forthcoming) for further information on the methodology of this aspect of the research
http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8685263
Three legal literature reviews exploring specific Conventions/Acts in relation to the law in Scotland. (Convention against Torture, Inhumane and Degrading Treatment, International [CAT] SMITH, R., TAIT, L., BALES, K., MCCONNELL, L. & RABAN-WILLIAMS, R. 2010. Mapping the Law of Scotland in Relation to International Human Rights Treaties: CAT & CPT. Newcastle: Northumbria Law School, ibid., International Convention of Economic, Social & Cultural Rights [ICESCR] FLANIGAN, D. 2011. Mapping the Law of Scotland in Relation to Economic, Social & Cultural Rights. Glasgow: Scottish Human Rights Commission, ibid. and Human Rights Act/ European Convention of Human Rights] NORMAND, A. & WEBSTER, E. 2010. Mapping the Law of Scotland in relation to International Human Rights Treaties – Civil and Political Rights. Glasgow: University of Strathclyde.
An analysis of all individual enquiries received by SHRC and all general intelligence on systemic human rights issues in Scotland collated by SHRC (2008-2010). Whilst only those inquiries received between 2008 and 2010 were analysed as part of Phase one of this scoping project, the mapping project continued to collate and review inquiries during 2011 as part of Phase two. All responses to SHRC’s 2009 national consultation. The original consultation document can be accessed at
http://www.scottishhumanrights.com/ourwork/publications/article/reportofthenationalconsultation
Initial Scottish data from the development of a “Human Rights Measurement Framework”. The HRMF is a new tool for evaluating the human rights position of individuals and groups in England, Scotland and Wales. It was developed by the London School of Economics and Political Science, CASE and the British Institute for Human Rights within a partnership project of EHRC and SHRC. More information can be found here: http://personal.lse.ac.uk/prechr/

3 During this process SHRC also developed a Stakeholder Database of third Sector organisations involved to some degree in the promotion of human rights in Scotland. This database provides SHRC with a greater understanding of the range of groups and organisations which view part of their work to be promoting human rights in Scotland and provided a sampling framework for groups to approach to participate in the primary data collection of this scoping project. This database is available to the public [http://maps.scottishhumanrights.com/] For further information on this project see: CRAIG, G. 2011. Mapping human rights organisations in Scotland. Durham: University of Durham, School of Applied Social Sciences.

4 Not all of the many issues identified within this framework could, however, be explored further in Phase 2. Accordingly, a prioritisation criteria filter was applied (see Appendix 1) in order to determine which would be explored in the focus groups.

5Since 1999 the way the United Kingdom is run has been transformed by devolution - a process designed to decentralise government. Devolution essentially means the transfer of powers from the UK parliament in London to the Scottish Parliament and the Scottish Executive (officially referred to as the Scottish Government since August 2007) in Edinburgh. The Scottish Parliament is a legislation-making body, passing bills in various areas of its many devolved responsibilities. The Scottish Parliament also has the power to raise or lower income tax (as changed by the Scotland Act 2012). Devolved areas of legislative competence to the Scottish Parliament include agriculture, forestry & fishing, education, environment, health, housing, justice, policing and courts, local government, fire service, economic development, some transport responsibilities and human rights. The UK government is responsible for national policy on other powers which have not been devolved - these are known as "reserved powers". These include the constitution, defence and national security, foreign policy, energy, immigration and nationality, social security and some transport responsibilities. Many themes in this scoping project engage equality legislation in relation to combating discrimination. Equal opportunities is a reserved matter (under Schedule 5 of the Scotland Act 1998 (Reservation - L2)), however, the reservation incorporates an exception in so far as the Scottish Government and the Scottish Parliament can impose certain duties which allows for scope

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for positive steps to be taken in relation to equality despite limitations on the powers available to the devolved administration.

6 Section 149 of the Act.

7 *"The public sector equality duty requires equality to be considered in all the functions of public authorities, including decision-making, in the design of internal and external policies and in the delivery of services, and for these issues to be kept under review. The public sector equality duty is set out in sections 149-157 and schedules 18 and 19 of the Equality Act. The general equality duty covers all public authorities named or described in Schedule 19 – Part 3 of the Equality Act 2010 together with those listed in the Equality Act 2010 (Specification of Public Authorities) (Scotland) Order 2010. The specific duties were created by secondary legislation in the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012. These specific duties came into force on 27 May 2012. Under the specific duties each listed authority is required to assess and review policies and practices i.e. impact assess"*. See http://www.equalityhumanrights.com/scotland/public-sector-equality-duty/non-statutory-guidance-for-scottish-public-authorities/ for further details.

8 The Care Commission was set up under the Regulation of Care (Scotland) Act 2001 ("the 2001 Act") in order to raise the standards of care by involving people who are cared for and working with people providing care. On 1st April the Care Commission's functions passed to a new body; Social Care and Social Work Improvement Scotland (SCSWIS) under the Public Services Reform (Scotland) Act 2010 and on 16th September 2011 Nicola Sturgeon, Cabinet Secretary for Health and Wellbeing, announced that SCSWIS would be re-named the Care Inspectorate and that regulations would be introduced to specify that all care homes would have a minimum of one unannounced annual inspection (BBC, 16/09/2011).

9 S. 45 of the 2001 Act

10 See thematic section 2 on Health for further details of healthcare standards.

11 See: http://www.scotland.gov.uk/Publications/2012/05/6469

12 ADAMS, L. 2009. Scotland's Secret Scandal - abuse of the elderly. The Herald, 12th October 2009.

13 The Scottish Government commissioned a module of questions on the August Wave of the Ipsos MORI Scottish Public Opinion Monitor (cited in (2011 Scottish Government Social Research) a quarterly telephone survey carried out among a representative sample of c.1,000 adults (18+) in Scotland.

14 Jacquie Roberts, then CEO of the Care Commission, raised concerns that by 2020 approximately 40 per cent of young people leaving school will need to enter the sector in order to cope with the projected increase in demand for services. She is quoted as stating that if population projections are correct and services continue at their current level of provision without an increase in resources, then by 2031 approximately 175000 people who are currently in receipt of services would not receive anything. She also stated that with a care sector that is unable to cope with the level of need, there may be an increased need to institutionalise older people which could increase the risk of human rights abuses ADAMS, L. 2009. Scotland's Secret Scandal - abuse of the elderly. The Herald, 12th October 2009.

15 See: http://www.scottishhumanrights.com/careaboutrights

16 http://www.scottishhumanrights.com/careaboutrights/evaluation

17 Powell v United Kingdom (2000) 30 EHRR CD 362 and Calvelli and Ciglio v. Italy [2002] Grand Chamber, application no. 32967/96, 17 January 2002.

18 Silih v Slovenia, Grand Chamber, 9 April 2009, application no. 71463/01, para. 192.

19 Silih v Slovenia, Grand Chamber, 9 April 2009, application no. 71463/01, para, para 196.

20 such as denial of food, water, sanitation See e.g. KALASHNIKOV v. RUSSIA, (Application no. 47095/99), JUDGMENT of 15 July 2002
CASE OF DOUGOZ v. GREECE, (Application no. 40907/98), JUDGMENT of 6 March 2001
CASE OF PEERS v. GREECE, (Application no. 28524/95), JUDGMENT of 19 April 2001
CASE OF PRICE v. THE UNITED KINGDOM, (Application no. 33394/96), JUDGMENT of 10 July 2001

21 CASE OF PRICE v. THE UNITED KINGDOM, (Application no. 33394/96), JUDGMENT of 10 July 2001

22 For a more complete overview of the relevant human rights in social care see SHRC, Care about Rights? http://www.scottishhumanrights.com/careaboutrights/

23 http://scottishhumanrights.com/news/latestnews/article/olderpeopleun

24 This could being care homes, at home or in other care settings such as hospital.

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25 Similarly in England, Panorama's documentary investigating systematic abuse at Winterbourne View Care Home in June 2011 highlighted allegations of serious abuse of care home residents BBC NEWS. 2011a. Government condemns shocking Winterbourne View abuse. BBC News [Online]. [Accessed 19th September 2012]..

26 This figure may well be higher as this is an issue likely to be under-reported.

27 Although there were several individuals whose contact with some family members was restricted or supervised and these were authorised by guardianship powers.

28 http://dementiascotland.org/news/files/MEDIA-RELEASE-comment-on-Jeanette-Maitland-May2012.pdf

29 The Care about Rights training programme can be accessed here:
http://www.scottishhumanrights.com/careaboutrights/welcomepage
Evaluation of the Care about Rights training can be accessed here:
http://www.scottishhumanrights.com/application/resources/documents/CaRfullevaluationfinalOct2011.pdf

30 In these circumstances the local authority retains a duty to provide aftercare support to a child who is looked after beyond school age until the 19th birthday or up until the 21st birthday if welfare requires it (See sections 17 and 29 of the 1995 Act). The Children (Leaving Care) Act 2000 provided for the transfer of financial support for young people aged 16 and 17 from the Department for Work and Pensions to local authorities. This was implemented in Scotland in April 2004.

31 Previously the Scottish Alliance for Children's Rights.

32 Autism spectrum disorder can cause a wide range of symptoms, which include difficulties in three forms of interaction:
problems and difficulties with social interaction – including lack of understanding and awareness of other people's emotions and feelings;
impaired language and communication skills – including delayed language development and an inability to start conversations or take part in them properly and unusual patterns of thought; and
physical behaviour – including making repetitive physical movements, such as hand tapping or twisting (the individual develops set routines of behaviour and can get upset if the routines are broken)
Source: http://www.nhs.uk/conditions/autistic-spectrum-disorder/Pages/Introduction.aspx (accessed on March 22nd 2012).

33 http://www.autism.org.uk/get-involved/campaign-for-change/our-campaigns/we-exist-campaign-for-a-scottish-autism-bill.aspx

34 http://www.autism.org.uk/get-involved/campaign-for-change/our-campaigns/we-exist-campaign-for-a-scottish-autism-bill.aspx

35 Often individuals with autism spectrum disorders (ASDs) can have problems relating to eating and difficulties surrounding their diet, arising from both over and under eating. Literature and research on this issue is limited, but what limited work has been done shows that dieticians can help children (and others with ASD) to better manage their diet and avert resulting health problems.
http://www.autism.org.uk/living-with-autism/understanding-behaviour/dietary-management-for-children-and-adolescents/dietary-management-over-eating.aspx

36 MENTAL WELFARE COMMISSION FOR SCOTLAND 2009. Summary of investigation into the care and treatment of Mr Q. Mental Welfare Commission for Scotland.

[37] This information is drawn from testimony provided to the Commission by Autism Rights in March 2011.

38 The Bill was introduced to Parliament on 26th May 2010 by Hugh O'Donnell, MSP and fell on 12th January 2011 when Parliament did not approve its general principles. Amongst its aims was to create a duty on Scottish Ministers to introduce an autism strategy.

39 http://www.scotland.gov.uk/Publications/2010/03/29164308/1

40 Independent Living in Scotland, a policy scoping study, prepared for the Disability Rights Commission by Reid Howie Associates, 2007, p 125 et seq; ILiS, Ready for Action, 2009, p 3.

41 The Independent Living Fund is an executive, non-departmental public body of the DWP, governed by a board of trustees.

42 The UN Convention on the Rights of Persons with Disabilities in Scotland, report of the joint information and consultation event in Glasgow, 22 January 2010, Scottish Human Rights Commission, Equality and Human Rights Commission, Office for Disability Issues, Scottish Government; EHRC & SHRC 2011. Being part of Scotland's story under the disability convention: The report of the joint Commissions' participation event with disabled people in Scotland about the United

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Nations Convention on the Rights of Persons with Disabilities. Glasgow: Equalities and Human Rights Commission and Scottish Human Rights Commission.

43 ILiS' definition of independent living demonstrates clearly the indivisibility and interdependence of all human rights and encompasses elements which are relevant to, among others Article 4 (general obligations), Article 8 (awareness raising), Article 9 (accessibility), Article 12 (legal capacity), Article 13 (access to justice), Article 18 (liberty of movement), Article 19 (independent living), Article 20 (personal mobility), Article 24 (education), Article 25 (health), Article 27 (work and employment), Article 28 (adequate standard of living and social protection), Article 29 (participation in political and public life), Article 30 (participation in cultural life, recreation and sport).See ILiS response to UK Joint Committee for Human Rights: Inquiry into the implementation of the Right of Disabled People to Independent Living, April 2011, paras 1.4-1.5.

44 91 of whom were within forensic learning disability services.

45 In relation to the funding of community care services, between 2007 and 2011 there has been an increase in net expenditure of 19.2 per cent (over £330 million) with the majority of expenditure relating to older people's services (between 62 and 63 per cent) PAYNE, J. 2011. SPICe Briefing: Adult Community Care- key issues. Edinburgh: Scottish Parliament.. As of March 2010, 66,222 people in Scotland, all of whom would be considered to be disabled people under the definition used in the Equality Act 2010, access home care and support in Scotland and 3,678 people in Scotland (again all of whom would be considered disabled people) access direct payments.

46 For more information see: http://www.ldascotland.org/index.php?option=com_content&view=Article&id=301:direct-payments-fall-in-glasgow-rise-in-edinburgh&catid=38:personalisation&Itemid=54 accessed on March 23rd 2012.

47 Scottish Government, Home care statistical return: a national statistics publication for Scotland, 2010.

48 This survey included the whole of the UK: 87 Councils in England; 12 in Wales, 9 in Scotland and 3 Health and Social Care Trusts in Northern Ireland. See http://www.ukhca.co.uk/pdfs/UKHCACommissioningSurvey2011.pdf

49 Iain Gray, Deputy Minister for Community Care, 29 March 2000, SP OR Vol. 5, col. 1120.

50 Adults with Incapacity (Scotland) Act 2000, s 1(3). Any person authorising an intervention under the Adults with Incapacity (Scotland) Act 2000 ("the 2000 Act"), must first be satisfied in relation to the principles of the Act set out in S.1 which include; that there is benefit to the adult, that the benefit cannot reasonably be achieved without the intervention and that the intervention must be the least restrictive option in relation to the freedom of the adult.

51 Shtukaturov v Russia, (application no. 44009/05), judgment of 27 March 2008.

52 Salontaji-Drobnjak v. Serbia, (application no. 36500/05), judgment of 13 October 2009; Stanev v Bulgaria, (application no. judgment 17 January 2012; DD v Lithuania, (application No. 13469/06), judgment of 14 February 2012 (the last two cases concerned placement of people with mental disorders in social care homes).

53 Alajos Kiss v Hungary, (application no. 38832/06), decision of 20 May 2010.

54 See for example for example: MENTAL WELFARE COMMISSION FOR SCOTLAND 2007. Older and Wiser. Mental Welfare Commission for Scotland.; CARE COMMISSION & MENTAL WELFARE COMMISSION FOR SCOTLAND 2009. Remember, I'm Still Me: Care Commission and Mental Welfare Commission joint report on the quality of care for people with dementia living in care homes in Scotland. Dundee & Edinburgh: Care Commission & Mental Welfare Commission. In relation to mental health law, see SCOTTISH GOVERNMENT 2009. Review of Mental Health Law Consultation Analysis. The Scottish Government.

55 Sections 275-276.

56 Section 259.

57 Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: report as presented to Scottish Ministers, March 2009, The Scottish Government, p 9.

58 [2002] 35 EHRR 1

59 Pretty v UK 66 BLMR 147 (2002) at p163.

60 [2009] UKHL45

61 The Queen (on the application of Tony Nicklinson) v Ministry of Justice [2012] EWHC 2381 (Admin). See http://ukhumanrightsblog.com/2012/08/16/locked-in-sufferers-challenge-to-ban-on-voluntary-euthanasia-fails-in-the-high-court/

62 SHRC, End of Life Assistance (Scotland) Bill, 14 May 2010, p7, http://archive.scottish.parliament.uk/s3/committees/endLifeAsstBill/evidence/ELA474.pdf

63 http://www.journalonline.co.uk/News/1010740.aspx

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http://www.bbc.co.uk/news/uk-scotland-16692686

[64] Prof Alan Miller, SHRC, Brian Taylor's Big Debate, broadcast 21 June 2012, web link: http://www.bbc.co.uk/programmes/b00mk70p

[65] See for example NHS Health Scotland and SHRC, Health Inequality Impact Assessment – Human Rights Case Studies, forthcoming, Edinburgh, 2012.

[66] A carer is defined as someone who provides substantial amounts of care on a regular basis for either an adult or a child in terms of the Social Work (Scotland) Act 1968 (S.12 AA) or the Children (Scotland) Act 1995 (S. 24). An unpaid carer is defined in the 2001 Census in slightly different terms as "looking after, giving help or support to family members, friends, neighbours or others because of long term physical or mental ill health or disability or problems relating to old age, excluding any care provided as part of any paid employment." PAYNE, J. 2011. SPICe Briefing: Adult Community Care-key issues. Edinburgh: Scottish Parliament.

[67] section 12AA

[68] Section 24

[69] This is now in the process of development with a charter expected in the spring of 2013.

[70] In total the Scottish Government has pledged to invest at least £8 million during 2011-12 in supporting carers through short break provision and the funding of NHS Board Carer Information Strategies.

[71] COMMUNITY CARE AND HEALTH (SCOTLAND) ACT 2002 NEW STATUTORY RIGHTS FOR CARERS: Accessed at http://www.sehd.scot.nhs.uk/publications/CC2002_10.PDF

[72] See http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/49020.aspx for further details. The Committee has also launched another inquiry into where Gypsy/ Travellers live.

[73] Accessible at http://www.scottish.parliament.uk/S4_EqualOpportunitiesCommittee/Reports/eor-12-03w-rev.pdf last accessed on 1st October 2012.

[74] See http://www.sccyp.org.uk/news/in-the-news/research-demonstrates-stark-differences-in-lives-of-young-carers for further information.

[75] See http://www.sccyp.org.uk/news/in-the-news/research-demonstrates-stark-differences-in-lives-of-young-carers for further information.