

UN Human Rights Council – Universal Periodic Review (UPR) – UK 3rd Cycle

1. Introduction

1.1 Alzheimer Scotland sets its priorities as an organisation in response to the experiences of people with dementia, their families and carers. Their insights and personal experience inform and drive our work at every level, shaping our services, our public policy work and our engagement with stakeholders across Scotland.

1.2 From this insight, we know that too often people with dementia, their families and carers find their rights restricted by the stigma and lack of knowledge which surrounds the condition. This includes restrictions placed on a person's ability to make decisions, including risk-aversion, limiting what a person can do. Within health and social care, there still exists a 'deficit model' approach focused on person cannot do rather than what they can. These often come about as a result of circumstances in which well-meaning attempts are made to protect the person from harm or do what is perceived to be in a person's best interests. However, it is often the case that doing so fundamentally fails to respect the person as an individual with unique experiences, interests and abilities, who can still actively and meaningfully engage with their community.

Alzheimer Scotland's submission is primarily concerned with the following recommendations made in the 2nd Cycle – 13th session:

- *110.32 'Continue to ensure that human rights principles are integrated in domestic laws.'*
- *110.44 'Take further measures for the promotion and protection of human rights, including those of migrants.'*
- *110.49 'Review national legislation to ensure equality and non-discrimination'.*
- *110.50 'Continue stepping up its efforts in tackling discrimination and inequality for all its citizens'.*
- *110.66 'Consider strengthening policies to combat discrimination in all areas, notably in employment and discrimination'.*
- *110.102 'Strengthen measures at reducing serious inequalities in access to health, education and employment, which still exist despite the adoption of the equality Act'.*
- *110.103 'Guarantee the enjoyment of economic, social and cultural rights, particularly in health, education and housing'.*
- *110.42 'Continue efforts in enhancing the welfare of segments of society and protect their rights'.*

- 110.101 *'Provide more resources for reforming the welfare system in order to make it better able to tackle poverty and worklessness, and reduce negative impact on social vulnerable groups'.*

2. Domestic Context

2.1 In Scotland, the public policy work around dementia has embraced a rights-based approach to be applied, in services, communities, by practitioners and the public alike. Through the Promoting Excellence Frameworkⁱ, Dementia Friendly Communitiesⁱⁱ, Dementia Friends Scotlandⁱⁱⁱ, Dementia Champions Programme^{iv}, the Dementia Care Standards^v, the Dementia Strategies etc. it is evident that a human rights are not simply an abstract concept, but one which can provide real impetus for societal and professional changes which improve the lives of people and challenge the stigma people have often faced.

Involvement

2.2 Increasingly, people with dementia, their families and carers are being invited to inform public policy work of governments, health boards and local authorities, sharing their expertise and experience of services and community support.

2.3 The Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) are well established national groups (in Scotland) which are excellent examples of how people with lived experience of a health condition can meaningfully be involved in the development of public policy. Both groups meet with Scottish Ministers and civil servants to discuss issues which matter to them and have been involved in the development and implementation of Scotland's dementia strategies. They also have informed national training programmes such as the Promoting Excellence Framework^{vi}, a training framework grounded in a rights-based approach, for all health and social care staff working with people with dementia, their families and carers.

2.4 As a result, public policy has progressed considerably in recent years to drive this shift towards a rights-based approach for people with dementia, including:

Charter of Rights for People with Dementia

2.5 Alzheimer Scotland worked in partnership with the Scottish Parliament's Cross Party Group on Alzheimer's and the Scottish Human Rights Commission to develop the Charter of Rights for People with Dementia (2009)^{vii}. The Charter restates the standards already set by the United Nations and other international instruments by recognising:

- The need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support.
- That people with disabilities must be guaranteed the fullest possible realisation of their human rights, including an opportunity to participate in and contribute to society, and where necessary, with the highest attainable standard of care.
- That discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.

2.6 The development of this Charter has been crucial as a foundation from which dementia public policy and strategy has been developed, including national standards for people with dementia and national Dementia Strategies to create transformational change.

Standards of Care for People with Dementia (2011)

2.7 The Standards of Care for Dementia in Scotland were developed in partnership with the Scottish Government and relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports they receive or the severity of their illness.

2.8 The Standards reflect the Charter of Rights for people with dementia and are written as statements of rights, for example 'I have the right to a diagnosis'. The standards apply to people with dementia and their carers from diagnosis to end of life and in every setting, including people living in their own homes, care homes or hospitals.

Scotland National Dementia Strategies (2010-13, 2013-16 and 2013-19)

2.9 Scotland's first National Dementia Strategy (2010-2013)^{viii} and second National Dementia Strategy (2013-2016)^{ix} have driven improvements in practice, including the provision of rights-based care and support. Over the life of these strategies, work has been prioritised to:

- Ensure that all care and support to people living with dementia, their families and carers promotes wellbeing and quality of life, protects their rights and respects their humanity.
- Improve services and support from diagnosis and throughout the course of the illness, including supporting the needs of carers. This support must be person-centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians.
- Redesign and transform services to ensure that they are adequately supported to deliver service effectively and efficiently.

2.10 Over the past year, the Scottish Government has actively worked with stakeholders across the health and social care sector to create a third National Dementia Strategy, working with Alzheimer Scotland to involve people with dementia, their families and carers to gather their views on what issues and themes should be central to the new strategy^x.

Legislation, Policy and Strategies

2.12 The Scottish Government has undertaken extensive reviews and introduced a number of pieces of legislation aiming to positively change people's lives including:

- The review of the Mental Health (Care and Treatment) (Scotland) Act 2003 through the Mental Health (Scotland) Act 2015 – this has removed provisions from the former which allowed for substitute decision making and improved rights around privacy.
- The consultation on proposals to amend the Adults with Incapacity Act (Scotland) Act 2000 in response to a Supreme Court ruling on deprivation of liberty – the proposals improve safeguards around settings where deprivation of liberty may occur both within hospital and community settings.

- In addition to these reforms, and as part of the development of a rights-based Mental Health Strategy, the Scottish Government has committed to a review of all Mental Health legislation by 2018.
- Introduction of the Carers (Scotland) Act 2016 which improved the rights of carers which improved carers rights in relation to assessment, access to services and inclusion in the decision making in relation to the cared-for person in hospital settings.

3. International Context

- 3.1 The European Convention on Human Rights (ECHR), incorporated into domestic law through the Human Rights Act (1998), and the Scotland Act (1998), as well as the international human rights treaties signed and ratified by the UK, provide a legal underpinning to the concept of a rights-based approach at a devolved level in Scotland. It is concerning that the UK Government has stated its intention to repeal the Human Rights Act 1998.
- 3.2 The Scottish Government has recently consulted on a new delivery plan for meeting its obligations under the United Nations Convention on the Rights of People with Disabilities (UNCPRD). As part of this, the Scottish Government has committed to approaching policy and legislation in a way which underpins supported decision-making and moves away from substitute decision-making, in line with the principles of Article 12 of the United Nations Convention on the Rights of People with Disabilities (Equal Recognition before the Law).
- 3.3 The delivery plan also committed the Scottish Government to reviewing the Adults with Incapacity (Scotland) Act 2000 and consulting on the Scottish Law Commission's review of the 2000 Act in relation to deprivation of liberty. (See also 2.12)
- 3.4 It is evident that the legal framework surrounding human rights, particularly at the international level, is extremely complex. For example, in relation to the individual's right to privacy (Article 8 of the European Convention on Human Rights (ECHR)) and the right to a fair hearing (Article 6 of ECHR), there is a balance to be struck between providing enough information to a proxy (where the person themselves lacks decision making capacity) to ensure a fair hearing takes place, without breaching the privacy of this person.
- 3.5 There is a broader balance to be struck with rights, particular within the international context. General Comment No.1 by the Committee on the Rights of Persons with Disabilities regards all forms of substitute decision making as discriminatory and in breach of multiple articles of the UNCPRD, including Articles 5 (Equality and Non-discrimination) and 12, amongst others.
- 3.6 However, we note that there are inconsistencies between UNCPRD and the ECHR, particularly with the former and the interpretation of Article 12 by the Committee on the Rights of Persons with Disabilities. The ECHR accepts that limitations of these rights, on the basis of a mental impairment, may be permitted subject to safeguards. We are further aware that the European Court of Human Rights (ECtHR) interpretation of the UNCPRD is divergent from that of the Committee, whilst still endorsing the Articles of the UNCPRD.
- 3.7 The conflicting nature of some of these rights and the complex and interconnected legislative framework which underpin them creates challenges in the application of rights in practice. This is an area which has not entirely been resolved and can prove difficult where the rights of different groups conflict. The Scottish Government should, as part of its commitment to

delivering on the UNCRPD and its obligations under the ECHR, work to provide guidance on how any conflicts should be accommodated.

- 3.8 Alzheimer Scotland notes the recent joint publication, 'Access to CRPD and SDG [Sustainable Development Goals] by Persons with Dementia'^{xi}, by Alzheimer's Disease International and Dementia Alliance International. This publication provides further detail on the specific problems experienced by people with dementia in relation to the CRPD. In addition, we note Three Jurisdictions Report^{xii} which specifically examines UK compliance with CRPD Article 12 in relation to incapacity legislation.

4. Next Steps

- 4.1 Alzheimer Scotland believes that there must continue to be a robust legal framework in place, not only to clearly enshrine the rights of people, but to provide a statutory footing which gives them the ability to hold governments at all levels to account, where they are not upholding the individual's rights. The recent examples in relation to deprivation of liberty^{xiii} demonstrate that even with robust legislation and guidance in place, alongside well-intentioned practice which may be deemed to be in a person's 'best interests', it is still possible for person's rights to be impinged upon. We therefore oppose the repeal of the Human Rights Act 1998.
- 4.2 However, it cannot be only national governments which are expected to proactively promote and uphold the rights of people. As Scotland enters into its first year of health and social care integration, it will be imperative that the new IJBs meaningfully involve, engage and respond to people with dementia, their families and carers. As these IJBs will have control of the design and commissioning of health and social care services within their local areas, these new bodies will have considerable decision making powers which will impact on people living with dementia.
- 4.3 Some progress has been made to transform the way in which people interact with social care services within Scotland, including through the Social Care (Self-Directed Support) Act 2013, which allowed people to have greater choice and control over how the money used to support them was spent. This legislation was explicitly rights-based, however, from our experience of working with people with dementia, we know that the uptake of self-directed support (SDS) has been limited. It is imperative that as IJBs begin to review and commission services, that this is reviewed to ensure that everyone has the opportunity to access SDS.
- 4.4 The Scottish Government and Scottish Parliament, from 2017, will assume competency over the some elements of the social security system. The Scottish Government is currently consulting on the implementation and operation the system, proposing measures to reduce the stigma around benefits and ensure that people within the system are treated with dignity and respect with control and choice of how they are supported. This is a positive development, however, we advocate that this system be rights-based in nature. It will be imperative to monitor this development closely to determine whether this transfer of benefits delivers meaningful improvements to people within the system.

5. Conclusion

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- 5.1 It is evident that human rights applied in practice and underpinned by statute lend considerable weight to the arguments for choice, participation, involvement and transparency in the way in which health and social care services are designed and delivered.

5.2 A rights-based approach, when delivered in practice, provides a framework which places the individual's choice and control at the centre of decision making whilst balancing responsibilities to safeguard the individual from harm, the broader public interest and the rights of others. This requires sustained training and development of the workforce who support people with dementia and their carers.

5.3 There is no doubt that there has been good progress towards embedding a rights-based approach in Scotland, with many strands taken forward since the last review in 2012, including supporting people to make decisions about their care and support, ensuring people can participate and contribute to their local community and ensuring staff are trained to provide the highest quality of care and support for people with dementia, their families and carers.

5.4 However, there are a number of areas in which further must be undertaken to ensure that the rights of people with dementia, their families and carers are upheld:

- Mechanisms should be in place at all levels of statutory services to ensure that people with dementia and their carers can meaningfully participate in the decisions that affect them, whether directly or indirectly. This includes services or supports they may themselves use, or policy, legislation and strategy which will impact upon them.
- The forthcoming devolution of some elements of the social security system to the Scottish Parliament must be rights-based and person-centred, and works to remove the stigma of the existing system.
- The review of mental health legislation must draw on the experience of people who have been affected by it, including those who have had to exercise proxy decision making powers.
- Statutory and non-statutory bodies across Scotland must be engaged and work to ensure that to ensure that the Human Rights of people are not undermined by the UK Government's intention to abolish the Human Rights Act or withdraw from the European Union.
- Further work must be taken to review the implementation of legislation, policies and strategies to evaluate their effectiveness as per their intentions, especially where the legislation aimed to give people greater choice and control in their own lives.

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21 September 2016

i i <http://www.gov.scot/resource/doc/350174/0117211.pdf> - Promoting Excellence Framework, 2011.

ii http://www.alzscot.org/dementia_friendly_communities - Dementia Friendly Communities, Alzheimer Scotland, 2013.

iii <http://www.dementiafriendscotland.org/> - Dementia Friends Scotland, Alzheimer Scotland, 2014.

iv <http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/our-work/dementia/dementia-champions-programme.aspx> - Dementia Champions Training Programme, NHS Education for Scotland, 2011.

v <http://www.gov.scot/Resource/Doc/350188/0117212.pdf> - Standards of Care for Dementia, Scottish Government (2011).

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- vi <http://www.gov.scot/resource/doc/350174/0117211.pdf> - Promoting Excellence Framework, 2011.
- vii http://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf - Charter of Rights for People with Dementia, 2009.
- viii <http://www.gov.scot/Resource/Doc/324377/0104420.pdf> - Scotland's National Dementia Strategy (2010-13), Scottish Government, 2010.
- ix <http://www.gov.scot/Resource/0042/00423472.pdf> - Scotland's National Dementia Strategy (2013-16), Scottish Government, 2013.
- x <http://www.gov.scot/Resource/0049/00497716.pdf> - Proposals for Scotland's National Dementia Strategy (2016-19), 2016.
- xi <http://www.alz.co.uk/sites/default/files/pdfs/access-crpd-dementia.pdf> - 'Access to CRPD and SDG by Persons with Dementia', Alzheimer's Disease International and Dementia Alliance International, 2016.
- xii <http://autonomy.essex.ac.uk/eap-three-jurisdictions-report> - Martin, Michalowski, Stavert et al., 2016.
- xiii
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/485122/DH_Consolidated_Guidance.pdf – 'Department of Health Guidance: Response to the Supreme Court Judgment/Deprivation of Liberty Safeguards', UK Government, 2015.