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Scottish Experience - human rights and supporting decision making for people with dementia and others with impaired decision making ability.

1 Overview: Scottish Government's policy on human rights.

The overarching policy of the Scottish Government is to integrate Human Rights principles across all social policies, through a series of implementation strategies set out in the Scottish National Action Plan for Human Rights (SNAP)ⁱ, which it describes as a roadmap for the realization of all internationally recognized human rights conventions.

SNAP was introduced in 2013, a new 3 year strategy is imminent. Top priority will be achieving Equality in Health, taking a holistic approach, including education, housing and income. The Health and Social Care Alliance (ALLIANCE) co-convenes, with NHS Scotland, the SNAP Health and Social Care Action Group. A website has been developed and film and written case studies have been produced to illustrate the application of human rights approaches in practice.

Scottish Ministers developed National Care Standards (2015)ⁱⁱ to ensure everyone in Scotland receives the same high quality of care no matter where they live. There are six main principles behind the Standards: Dignity, Privacy, Choice, Safety, Realising Potential, Equality and Diversity.

2 Health and social care policy for Self Directed Support

Social Care (Self-Directed Support) (Scotland) Act 2013, came into force in April 2014, SDS Strategy – Plan 3, 2016-2018 (imminent).

This Act places a duty on local authority social work departments to offer people who are eligible for social care a range of choices on how they receive their social care and support. The intention is to offer choice, control and flexibility, which includes Direct Payments, as an option to help people to live the life they want. This is the equivalent of Australia's NISPD. Alzheimer Scotland and other specialist voluntary organisations have statutory funding in some areas to run projects to support the uptake of direct payments.

How is it working?

'Engagement Activities' in February 2016 to gain feedback on implementation highlighted the need to build an evidence base around what a different SDS makes. Whilst existing data suggests that good outcomes focused practice was increasing, the challenges identified included: problems in commissioning flexible supports; good outcome focus and creative practice restricted on grounds of risk; austerity-cuts in services restricted outcome focused practice; awareness of SDS lacking for professionals, people they support and unpaid carers; too much bureaucracy. Significantly, in terms of promoting SDS, this policy has given rise to an increase in applications for welfare and financial guardianship in order to access to funds. There is considerable confusion around capacity assessment i.e. ability to manage funds and ability to choose how it is spent. Both the Mental Welfare Commission, which monitors Welfare Guardianship orders and the Office of the Public

Guardians have expressed concern that the increase in the number of guardianship orders, an unintended consequence which is undermining rather than enhancing the rights of adults in terms of compliance with Article 12.

3 National Dementia Strategies

The Scottish Government introduced the first 3-year National Dementia Strategy in 2010, (the 3rd is imminent)ⁱⁱⁱ. The Strategy is underpinned by human rights principles, a major achievement which has had a widespread influence on the forthcoming mental health and learning disability strategies. Alzheimer Scotland has championed the rights of people with dementia over many years and, in collaboration with the Scottish Human Rights Commission, produced a Charter of Rights for People with Dementia and their Carers (2009), sponsored by the Scottish Parliamentary All-Party Group on Alzheimer's. The Charter was adopted by the Scottish Government and is embedded in the Dementia Strategy, Dementia Care Standards and Training for Excellence programme. The Charter is based on a raft of international rights conventions including UNCRPD and guided by the PANEL approach.

A continuing priority in the dementia strategies is to improve timely diagnosis, with the provision of a guaranteed minimum of 12 months post diagnosis support from a named professional to ensure continuity. Post diagnosis support is predicated on a '5 Pillar Model' designed by Alzheimer Scotland, which includes helping the person to come to terms with the diagnosis and continue to participate in the activities that are important to them. Another Pillar is to support the person to make decisions about their future life and care before the dementia progresses.

Individuals are offered information on advance care planning, power of attorney, Advance Directives and other financial and legal issues.

These provisions offer opportunities for individuals to remain in control of their own lives as far as possible, ensuring that others know their ‘will and preferences’. However, no specific training is provided to staff on approaches to supporting decision-making. As anticipated, earlier diagnosis and support has given rise to a rapid increase in the number of powers of attorney applied for and registered. Some health boards have very active campaigns to promote power of attorney e.g. ‘My Attorney’ awareness campaign run by Grater Glasgow and Clyde Health Board. This is a response to the demographics, with an ageing population number with dementia is increasing rapidly and without family members taking on the role of attorney, the state would have to put measures in place which would place a heavy burden on the public purse.

There is currently no research into implementation of post diagnosis support and feedback from recent government ‘dementia dialogue’ consultations is that provision and quality of service is patchy.

Adults with Incapacity (Scotland) Act 2000 – background

Alzheimer Scotland (AS) coordinated the campaign for radical reforms to the law to protect and promote the rights of adults with impaired decision making capacity due to a mental disorder, including dementia, learning disability, mental illness, acquired brain injury and other conditions, or physical disability such as severe stroke. AS recognized that people with dementia represented the largest group in society to benefit from reforms and that provisions would transform the rights of family members trying

to support them and manage their financial affairs.

Powers of attorney and guardianship are the key provisions giving legal authority to one or more persons to enable an intervention on the basis of the principles embedded in the Act.

The intention of the Act is to promote the autonomy of an individual with impaired decision making capacity, to support them to make their own decisions as far as possible and require others to support them to do so, within a substitute decision making framework.

Capacity must be assumed unless there is evidence to suggest otherwise. A diagnosis of a mental disorder does not mean the person lacks capacity. It must not be assumed that a person lacks capacity just because they make an unwise decision.

The principles must apply to any decision or action which an attorney or guardian is considering on behalf of the adult.

Principles:

Any decision made on behalf of the person with impaired capacity must:

- benefit the person
- be the least restrictive of the adults freedom as possible whilst still achieving the desired benefit
- take account of the persons past and present wishes, providing every assistance to aid communication as appropriate to the needs of the individual
- take account, as far as is reasonable and practicable, the views of others with an interest in the welfare of the adult

- encourage the adult to use existing skills and where possible to develop new skills.

Any decision or action must be for the benefit of the person and relate to their specific needs and circumstances. It should be noted that ‘benefit’ is used in preference to ‘best interest’. Within AWI there is no hierarchy of principles. The information gathered in considering each of the principles should help reach a decision which will be of most benefit to the person and with the least intervention necessary.

Currently around 73% of welfare guardianship appointments are family members (private guardians) and the remainder local authority – the local authority having the duty where there is no other suitable person available.

The local authority has a duty to both supervise and support private welfare guardians, to visit within 3 months of being appointed and twice a year thereafter. Recent statistics published by the mental welfare commission indicate that 41% of private guardians appear to have had no supervisory visit within the last 6 months and evidence suggests that of those, 64% of adults with incapacity have not received a visit.

Supervisory visits by social work departments support guardians to properly use their powers in line with the principles of the Act.

The public guardian has a duty to supervise financial guardians i.e. to make sure they are carrying out their functions properly but only do this through a paper exercise unless someone raises a complaint.

There is no requirement within legislation or regulations for welfare for

attorneys to be supported by anything other than the provision of information. Local authorities are only required to provide information to welfare attorneys on request.

Attorneys have the same duty to apply the principles as guardians, with many of the same responsibilities and they may have been granted considerable decision-making powers. Unlike guardians, attorneys have the additional challenge of determining when the person has lost capacity sufficiently to start using the powers granted unless specific conditions have been identified in the power of attorney document. They face the same tough decisions as court appointed guardians. The lack of support for attorneys has been a constant concern for voluntary organisations representing the interests of adults with impaired decision making capacity and their families.

The lack of adequate information, support and training for lay proxies emerged from research into the early implementation (2003/2004)^{iv}. This and other findings led the Scottish Government to introduce a three year action programme to improve policy and practice (2004-2007). Of particular concern was the general lack of awareness and understanding of the principles across the health and social care professions as well as family members appointed as guardians. An information strategy was put in place, which included DVDs (Making decisions – your rights – for people with dementia, learning disability and carers), wallet cards, solicitors reminded of their duty to inform etc. In response to another key issue concerning assessment of functional capacity a guide was produced on: ‘Communication and Assessing Capacity for social work and health care staff’ (2008)^v. It was also useful for family members and others supporting the person with decision-making difficulties.

The research also gave rise to the thorny issue of deprivation of liberty or restrictions on freedom in terms of: definitions; what is lawful for an attorney with welfare powers to do attorney – can it ever be lawful to move someone with dementia to a care home against their will or does that necessitate an application for a guardianship order with special powers to do so? It also gave rise to the issue of whether a local authority could move someone from hospital to a care home, where the person is compliant but not capable of giving consent.

An amendment included in the Adult Support and Protection (Scotland) Act 2007 removed the requirement for guardianship, which took time and cause delayed discharges. However some local authority solicitors and others have never been happy that this amendment was compliant with ECHR and it remains a live issue, currently under review, with a Scottish government consultation taking place on recommendations in the recent Scottish Law Commission's Report.

The Scottish government's review of AWI coincides with the forthcoming review of UK's capacity/incapacity laws by the UNCRPD Committee with particular reference to Article 12. This happy coincidence has created an impetus bodies such as the Mental Welfare Commission and service user groups and voluntary organisations representing their interests to press for the Scottish Government to undertake a wider review. In response the Scottish government has request comments on what other changes there should be to ensure the Act working as intended. There is concern, for example, that the rise in the number of guardianship orders may be an unintended consequence of the SDS Act, and that non-specialist judges are awarding plenary powers

in cases when there may be less restrictive options.

About Dementia and decision making

People with dementia have a lifetime's experience of making decisions for themselves, however dementia is a progressive condition which gradually erodes their capacity to make some or all decisions in their own interests. During the course of the illness, individuals lose the ability to make judgments about decisions in the way that they normally would do. They lose the skills needed for making rational, legally binding decisions and managing finances. Their ability to assess risks diminishes to the extent that they may put themselves or others at risk in the environment or at risk of abuse.

Research on the role of emotion in decision-making by Professor Hilary Brown, Canterbury University,^{vi} provides valuable insights into the impact of dementia in relation to refusal of support from services. She concludes that emotions seem to provide an essential driving force in deciding; and explores the influence of a person's: history and memories, their drive and motivation, their mood and stability and their openness to influence.

It is as if the unknown can come to seem so frightening or unimaginable to the extent that a person would prefer to keep to the familiar routine and avoid new experiences at all costs – people with dementia may find themselves governed more by this kind of overwhelming fear than by their assessment of the possibilities, this inevitably affects their decision-making and locks them into a distressing situation. Such cases are not uncommon, being faced daily by health and social care professionals especially where vulnerable adults are prone to self-neglect.

Family members, partners and friends have the complex task of moving between supporting the person to make their own decisions, to making decisions together, and when necessary using the powers granted to them to act as substitute decision-makers. They are faced with the need to understand how and when to intervene.

The research project described below was motivated by both an accumulation of knowledge, from different sources, of the experiences of carers who were appointed as attorneys or guardians under the Adults with Incapacity (Scotland) Act 2000; and concern that the rights of people with dementia were being undermined by a lack of compliance with the principles in the Act and poor practice in assessing capacity.

Dementia: Autonomy and decision-making. Putting Principles into Practice. Research summary and recommendations for policy and practice. (2012)^{vii}

Methodology

Qualitative research methodology: semi-structured, individual interviews and small group discussions with lay proxies in Scotland and England; and as a comparator, with lay proxies in the Netherlands and Berlin (where formal guardianship training and support networks receive statutory funding). Multi-disciplinary roundtable meetings were held in Edinburgh, London, Rotterdam and Berlin.

About the carers who took part in the study

Most of the 100 carers who volunteered to participate were family members aged between 30 and 80; equal numbers of male and female. A large proportion were 'lone' carers and felt very isolated, even where other family members were near by.

Key findings from lay proxies

1 Most carers reported that at the time of diagnosis no-one explained what it would mean for the future and no advice was given about legal issues, no one spoke to the person diagnosed about the benefits of advance care planning or appointing an attorney.

2 Some carers were faced with the more expensive and complicated option of applying for a guardianship order because the diagnosis was left too late for the person to appoint an attorney

3 Most lay proxies were not aware of the codes of practice etc. and do not know about the principles they were required to follow.

Many were unsure of the powers granted and did not know there were limits to the decisions they were able to make.

4 Carers said that on a day to day basis they did not always know how to judge whether the person had capacity when faced by them insisting on doing something risky. This was a cause of considerable concern and anxiety.

5 Many carers said that they experienced difficulties in the context of:

- managing relationships – coping with conflicts with other family members, professionals or the person themselves;
- convincing health and social care professionals that the person lacks capacity e. to manage self-care without help, as the person presents well at the time of the visit.
- Managing their own emotions and those of the person with dementia
- Managing their time.
- Knowing their rights/rights of the adult, when challenged or when choice and standards were poor.
- Carers felt that, in a crisis situation, the need to apply for guardianship was sometimes thrust upon them by professionals, with little chance to consider the care options/
- Welfare guardians generally found supervision systems were unsatisfactory, being unable to access support when needed.

Research in 2012 and in 2016 by the Mental Welfare Commission confirmed that many local authorities are not complying with their supervisory duties under AWI because the system is ‘demand driven’ and numbers on guardianship are increasing and resources are reducing).

- Welfare attorneys generally did not know where to go for help when faced with challenging situations and were reluctant to approach the local authority or the OPG in case they were judged as failing.
- Carers expressed an overwhelming sense of isolation in carrying

out their task; many said they had no one to speak with about the difficulties they face in relation the decision-making.

- The few carers who had been offered self-directed support with individual budgets felt it worked well.
- Carers attending training and information days on legal and financial issues had found these helpful (run on an adhoc basis by specialist voluntary organisations and some by OPG).

What carers wanted

All but a few carers in the study said that, if offered, they would have attended local training sessions either before or at the time of taking on powers. They also wanted an expert professional to consult with at times of difficulty, and an ongoing support network.

Professionals who participated in roundtable discussions identified with the issues raised by carers and said they resonated with their own experience.

Key recommendations

1 Scottish Government to recognize the unique responsibilities of lay proxies and strengthen support and protection for the person with impaired decision-making capacity, by introducing a national, low cost, easily accessible education programme for proxies or potential proxies. Stakeholder representatives suggested that a national standard course could be devised and delivered through local colleges in collaboration

with specialist voluntary organisations.

The UN acknowledges that providing appropriate decision-making support in accordance with the CRPD will require effort and financial investment and suggest this might involve redistribution of some of the existing resources currently used for substitute decision-making provisions.

The UK signed the Convention in 2010 but the full implications of this have yet to be realized in relation to our capacity laws.

2 The Scottish Government to review AWI to consider:

- A simplified form of graduated guardianship where powers needed are limited e.g. to access Self Directed support and Direct Payments
- To strengthen the principles in the Act to make support for decision making explicit.
- To revise codes of practice to clarify best practice in compliance with the UNCRPD in relation to supported decision-making; conflicts of interest and undue influence
- Clarify the concept of ‘deprivation of liberty’ in law and provide more detailed guidance on good practice – what it is lawful for attorneys or guardians to do in relation to deprivation of liberty and restrictions on freedom.

The gravity of taking on the responsibility of being an attorney or guardian cannot be underestimated, as it profoundly affects the human rights of the person over whom powers have been granted. In the difficult and complex situations often faced by lay proxies there is little support to help them reach decisions and carry them through.

From discussions about how they made decisions, it emerged that their common-sense approach reflected the principles and this worked well when matters were straightforward.

However they felt that knowledge of the principles would have been particularly empowering in the face of challenges by other family members, professionals or other agencies.

Adults with Incapacity (Scotland Act 2000 under review)

1 What constitutes deprivation of liberty or restrictions on freedom is an ongoing issue and highlighted by the *Bournwood* and *Cheshire West* cases in England. These cases revolved around keeping a person in a care environment – hospital or home, where they are compliant, not objecting, but not able to give informed consent.

As a consequence the Scottish Law Commission has carried out a review of the Act with specific reference to deprivation of liberty. The Scottish Government has been consulting on its recommendations and asked for additional views on how the Act might be improved.

2 The rise in the number of welfare guardianship cases is a cause for concern, particularly regarding adults with learning disability. This

appears to be exacerbated by assessments for Self Directed Support and Direct Payments in particular. In too many cases it appears that decision makers capacity is being undermined and carers are being required to apply for guardianship in order to access payments. The Act makes provision for the management of finances at a lower level (part 3) but this appears to be considered insufficient.

Also of concern is the rise in the number of young people with learning disabilities and autism on guardianship orders. There is a lobby for the diagnostic criteria of learning disability to be removed from AWI (the same might also apply to dementia)

3 AWI principles need to be strengthened to explicitly recognize that all possible action must be taken to support the individual to make their own decision. Supporting their ability to communicate their own decision falls short.

4 Proposals for SDM within a graduated guardianship system
The Mental Welfare Commission with the Centre for Mental Health and Incapacity Law, Napier University, Edinburgh have been working together to raise awareness of UNCRPD Article 12 and the Commission is launching a good practice guide to SDM, written by Prof. Jill Stavert, Director of the Centre. At the time of writing the author has received and unpublished paper by Colin McKay, CEO, Mental Welfare Commission, putting forward two options for graduated guardianship, one for a three tier system and the other proposed by the Sandra McDonald, Public Guardian, for a four tier system (a proposal first put forward some years ago). Both proposals include the appointment of an informal supporter. (I have requested permission to share this paper and hope to be able to do

so in advance of the roundtable).

The Scottish Government in considering responses to its consultation is considering supporting an event to consult on proposals for wider reform including supported decision making in the Spring of 2017.

5 The Essex Autonomy Project,^{viii} was commissioned to carry out an assessment of mental capacity/incapacity legislation in the three legal jurisdictions of the UK, to provide support to the UK officials who will be involved in the forthcoming UN Review of UK compliance with the UNCRPD, and to make recommendations in support of ongoing efforts across the UK to reform legislation to achieve UNCRPD compliance. The outcome is the Three Jurisdictions Report (2016).

Each Act provides, in a different way, for the provision of support for a person before it can be said they lack capacity or incapable in relation to a particular act or decision. The most developed of the Acts in this regard is the MCA (England and Wales), which sets out a series of steps that must be taken prior to any determination that the person lacks capacity to take the decision question. The NI Mental Capacity Act is based on MCA but goes further in requiring the appointment of a supporter.

The Essex Autonomy research team carried out a forensic analysis of UK legislation and compliance with UNCRPD and issues arising from the interpretation of the Convention by its Committee in CG1 and consulted with a wide range of experts/stakeholders. The report concludes that the UK legislation is non-compliant but remediable and sets out 10 recommendations, many of which are under active consideration by both the Scottish Government and UK Government.

References

- ⁱ Scottish Government: Action Plan on Human Rights (2013)
- ⁱⁱ Scottish Government: National Care Standards (2015)
- ⁱⁱⁱ Scottish Government ‘National Dementia Strategy
- ^{iv} Killeen j. myers f. et al (2004) Learning from Experience. Rsearch Studies, Scottish Executive and survey of welfare guardians (unpublished 2006).
- ^v Scottish Government: Adults with Incapacity (Scotland) Act 2000 – Communication and Assessing Capacity. A Guide for social work and health care staff. (2008)
- ^{vi} Brown H. and Marchant L. Best Interests Decision-making in Complex Cases: a report of a study commissioned by the Office of the Public Guardian (2011)
- ^{vii} Killeen J. Dementia:autonomy and decision-making. Putting principlles into practice. Research Summary and recommendations for policy and practice. Alzheimer Scotland (2012)
Killeen J. Dementia: making decisions. A practical guide for family members, partners and friends with powers of attorney and guardianship. Alzheimer Scotland (2012)
- ^{viii} Martin w. et al: Three Jurisdictions Report. Towards compliance with CRPD Art.12 in Capacity/Incapacity legislation across the UK. Essex Autonomy Project Position Paper. University of Essex. (6 June 2016.)