

Response ID ANON-3GJP-753V-9

Submitted to **Adults with Incapacity Reform**

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Chapter 1 - Background, current law and glossary of terms

Chapter 2 - Summary of proposals

Chapter 3 - Restrictions on liberty

Do you agree with the overall approach taken to address issues around significant restrictions on a person's liberty?

Yes

Please explain your answer.:

We believe this approach to be a sensible and positive one, reflective of the need to recognise the ways in which restrictions can apply not only within certain settings but in certain approaches to delivering care. The terminology of 'significant restriction' rather than 'deprivation' is a helpful change given that it more accurately describes the careful and delicate decision making that needs to go into determining whether restrictions are necessary and which do not always result in complete eradication of liberty, nor should they, as is implied through the use of 'deprivation'.

In particular we are suggesting that significant restrictions on liberty be defined as the following;

Yes

Please give reasons for your answer.:

This serves as an acceptable high level definition but requires far more clarity in the development of accompanying guidance. For instance, the consultation document outlines that the use of standard security cameras would not amount to significant restriction of liberty but, as highlighted by Scottish Care members, does not indicate whether cameras installed by relatives of an individual in a more covert way would be included. There are also potential questions around what 'close observation' means in practice, in a care home for example, and how the correct balance is ensured between upholding a duty of care to keep a person safe and what would amount to significant restrictions on liberty. From a human rights perspective, it is also important to balance rights such as the right to privacy of other care home residents through, for example, lockable bedroom doors, versus not imposing significant restrictions on another individual in terms of their access to parts of the premises. It is practical interpretations such as these which need to have more direction in guidance in order to avoid misunderstanding or misuse of the legislation.

Are there any other issues we need to consider here?

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Chapter 4 - Principles of Adults with Incapacity legislation

Do you agree that we need to amend the principles of the AWI legislation to reflect Article 12 of the UNCRPD?

Yes

Please give reasons for your answer.:

It is positive to see legislation being amended to better reflect and uphold a human rights approach, which Scottish Care would fully endorse. However it needs to be explicit that the terms of the UNCRPD relate to and apply to individuals who are diagnosed with dementia as this is to always appreciated or acknowledged.

Does our proposed new principle achieve that?

Yes

Please give reasons for your answer.:

It is the putting into practice rather than the principle which raises questions here.

The new principle calls for demonstration that all practical help and support around decision making has been given without success. However, it is unclear who would be required to evidence this despite it being a significant responsibility. Whilst this may lie with GPs, it is increasingly likely that care providers and their already stretched workforce would end up having to assume this responsibility in ways they would struggle to achieve due to a lack of capacity and training to do so. To assume this without clarity or consideration of resource implications for who the responsibility falls to would be unacceptable.

Additionally, it is not clear where and when practical help and support should be sought and equally where and when this should be demonstrated. This risks the principle not being enacted in a consistent way which ensures that everyone to whom the AWI legislation applies is treated fairly and equitably. It also does not account for the matter of fluctuating capacity.

Is a further principle required to ensure an adult's will and preferences are not contravened unless it is necessary and proportionate to do so?

No

Please give reasons for your answer.:

We believe that an individual's will and preferences underpin all the other principles and it would therefore not be necessary to add another. Instead, further explanation within guidance around this would be sufficient.

Are there any other changes you consider may be required to the principles of the AWI legislation?

No

Please give reasons for your answers.:

Chapter 5 - Powers of attorney and official supporter

Do you agree that there is a need to clarify the use of powers of attorney in situations that might give rise to restrictions on a person's liberty?

Yes

No

Please give reasons for your answer.:

Any steps which can provide more clarity as to the powers and responsibilities of a power of attorney are helpful as there can be significant misunderstanding and lack of awareness as to what these powers do and do not apply to, which are compounded when trying to enact them at difficult and often traumatic times.

Again, in principle, advance consent provisions would alleviate some of this but in reality, it is extremely difficult to get people to consider a hypothetical future scenario particularly if they have no prior experience of similar situations. Whilst it may support some people, for most it is likely to add another level of complexity to already complicated situations and dynamics.

It is unclear how these advance provisions would account for changing preferences, fluctuating capacity and even negotiating complex family dynamics in a meaningful way. Whilst the proposals suggest a need for regular reviews, it is again unclear as to the frequency of these in what in reality can be a constantly changing situation or who would be monitoring these provisions.

Is there a need to clarify how and when a power of attorney should be activated?

Yes

If you have answered yes and have views on how this should be done, please comment here.:

Whilst we do not have any clear views on how powers should be activated, Scottish Care members have stressed the problematic lack of overview of powers of attorney, which can result in misuse of powers and influence in ways that do not appropriately reflect the will and preferences of the grantor. This can leave care providers in a difficult middle ground between the individual and their power(s) of attorney. There therefore requires to be much clearer and consistent information imparted to powers of attorney about their role and how it can and cannot be used, and an authority to monitor this.

Do you think there would be value in creating a role of official supporter?

No

If you have answered yes, please give us your views on how an official supporter might be appointed.:

Whilst having access to information at the behest of the individual would be positive, we are not convinced of the benefit of a distinct 'official supporter' role for someone living with increasing cognitive impairment and therefore decreasing decision making ability.

A formal role could lead to conflicts between the official supporter and powers of attorney, therefore creating another layer and leading to decision making becoming an even more complicated process.

What's more, if it is onerous to become an official supporter, it is unclear whether people would seek to undertake this as they may choose to offer support in an 'unofficial' way instead.

Instead, we believe the promotion and availability of advocacy may be more valuable.

Countries that have created a role of supported decision maker have used different names, such as supportive attorney in Australia, or a 'Godman in Sweden, meaning custodian. We have suggested 'official supporter'. Do you think this is the right term?

Not Answered

If you selected 'Prefer another term', please give details.:

Chapter 6 - Capacity assessments

Should we give consideration to extending the range of professionals who can carry out capacity assessments for the purposes of guardianship orders?

Not Answered

If you answered yes, can you please suggest which professionals should be considered for this purpose?:

We are undecided as to the benefit of extending the range of professionals. The challenge of assessing capacity can be difficult and complex enough without widening the scope of who can do this. However, there would be some merit in ensuring that the professional who undertakes this has an ongoing understanding of the individual rather than making an assessment with little context at a particular point in time, given the variable nature of capacity and the factors which can influence it. We are clear that capacity, now and going forward, should only be assessed by those competent to do so and who know the person being assessed.

Our concern would be that to widen this would give some individuals, for example care home residents, less access to GPs and other equivalent medical professionals therefore resulting in unfair treatment compared to other individuals.

We would also want to understand what training would be available to such professionals to ensure their competency in undertaking capacity assessments.

It should also be recognised that even if the range was to be extended, not every individual in those designated roles would want to undertake such assessments and nor should this be expected of them.

Chapter 7 - Graded guardianship

Do you agree with the proposal for a 3 grade guardianship system?

No

Please give reasons for your answer.:

There are a number of reasons why Scottish Care members do not agree with a graded guardianship system:

- It creates more complication and bureaucracy for those seeking guardianship.
- There is no clarity as to how guardians would be monitored over the duration of their guardianship. This would need to be an objective third party with appropriate powers.
- There is no system for reminding someone when their guardianship runs out or clarity around whose responsibility it is to remind the guardian that they may need to reapply.
- It puts care providers in a vulnerable position given that they do not have the authority to have overview or influence over someone's guardian.
- It would require significant investment in ensuring a sufficient level of public understanding of the various grades.
- There should not be an expectation on care providers to become guardians. This would not be appropriate where they have direct, contractual care responsibilities relating to the individual..

Our intention at grade 1 is to create a system that is easy to use and provides enough flexibility to cover a wide range of situations with appropriate safeguards. Do you think the proposal achieves this?

Yes

Please give reasons for your answer.:

This is the most positive element in that it enables guardianships to be put in place more easily.

Are the powers available at each grade appropriate for the level of scrutiny given?

Yes

Please give reasons for your answer.:

We are suggesting that there is a financial threshold for Grade 1 guardianships to be set by regulations. Do you have views on what level this should be set at?

We are suggesting that there is a financial threshold for Grade 1 guardianships to be set by regulations. Do you have views on what level this should be set at? :

We believe that £50,000 would be an appropriate level.

We are proposing that at every grade of application, if a party to the application requests a hearing one should take place. Do you agree with this?

Yes

Please give reasons for your answer.:

It is very important that at such a critical time that individuals believe that they are being 'heard' and that their voice is being taken account of and that they feel that they have recourse in law.

We have listed the parties that the court rules say should receive a copy of the application. One of these is 'any other person directed by the sheriff'. What level of interest do you think should be required to be an interested party in a case?

What level of interest do you think should be required to be an interested party in a case?:

The person or persons should have had contact with or experience of the individual for a specified period of time or are directly involved in their care and treatment.

We have categorised grade 3 cases as those where there is some disagreement between interested parties about the application. There are some cases where all parties agree however there is a severe restriction on the adult's liberty. For instance very isolated and low stimulus care settings for people with autism, or regular use of restraint and seclusion for people with challenging behaviour. Do you think it is enough to rely on the decision of the sheriff/tribunal at grade 2 (including a decision to refer to grade 3) or should these cases automatically be at grade 3?

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Grade 3

Please add any further comments you may have on the graded guardianship proposals.

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Do you think our proposals make movement up and down the grades sufficiently straightforward and accessible?

No

Please give reasons for your answer.:

Do you agree with our proposal to amalgamate intervention orders into graded guardianships?

Yes

Please give reasons for your answer.:

Do you agree with the proposal to repeal Access to Funds provisions in favour of graded guardianship?

Yes

Please give reasons for your answer.:

Do you agree with the proposal to repeal the Management of Residents' Finances scheme?

Yes

Yes

Please give reasons for your answer.:

Chapter 8 - Forum for guardians

Do you think that using OPG is the right level of authorisation for simpler guardianship cases at grade 1?

Not Answered

Please give reasons for your answer.:

Which of the following options do you think would be the appropriate approach for cases under the AWI legislation?

Not Answered

Please give reasons for your answer.:

Please also give your views on the level of scrutiny suggested for each grade of guardianship application.

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If you have any further comments on the proposals for the forum, please add them here.

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Chapter 9 - Supervision and support for guardians

Is there a need to change the way guardianships are supervised?

Yes

If your answer is yes, please give your views on our proposal to develop a model of joint working between the OPG, Mental Welfare Commission and local authorities to take forward changes in supervision of guardianships.:

This would be positive but must involve revisiting and reimplementing a formal multidisciplinary review process. Scottish Care members have highlighted that at the point of permanent admission to a care home and also for people supported at home, it can be extremely difficult to access social work and/or mental health services even when individuals are at serious risk. Not only is this dangerous and discriminatory but it would mean the proposed model wouldn't work as a way of supervising guardianships if such bodies have limited or no engagement with many individuals. For it to work, the responsibilities that lie with these bodies must be clearly outlined and routinely fulfilled. To achieve this, Scottish Care members have suggested that locality management teams would be helpful.

If you consider an alternative approach would be preferable, please comment in full.

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What sort of advice and support should be provided for guardians?

What sort of advice and support should be provided for guardians?:

Information and advice regarding their duties and obligations in their role as guardians. This has to be consistently available and accessible in a number of ways. It must be recognised that many guardians are older and their own needs must be taken into account when ensuring they understand and can fulfil their duties as a guardian.

Do you have views on who might be best placed to provide this support and advice?

No

Please give reasons for your answers.:

Do you think there is a need to provide support for attorneys to assist them in carrying out their role?

Yes

If you answered yes, what sort of support do you think would be helpful?:

Clear, consistent and regularly updated information about their responsibilities as well as information they can pass on to guardians in accessible formats.

Chapter 10 - Order for cessation of residential placement, short term placement order

Do you agree that an order for the cessation of a residential placement or restrictive arrangements is required in the AWI legislation?

Yes

If so, does the proposal cover all the necessary matters?:

We agree that the cessation of a residential placement should only be considered by appropriately trained and engaged individuals. Regardless of the circumstances of initial placement and residency the nature of care home life is such that many individuals 'settle' and view the home as a place where they feel comfortable. Any alteration can be upsetting and disturbing especially for individuals with conditions such as advanced dementia and this should be handled carefully and cautiously.

Do you agree that there is a need for a short term placement order within the AWI legislation?

Yes

Please comment as appropriate.:

We agree that there are particular and specific circumstances which would merit a short term placement. We believe that the safeguards and measures outlined in the consultation should give sufficiency of reassurance to ensure that the adult's wishes and feelings have been acknowledged and taken into account. We would suggest that additional protection in such circumstances would be achieved through the right to access independent advocacy similar to the provisions in the Mental Health Care and Treatment legislation.

Do you consider that there remains a need for section 13ZA of the Social Work (Scotland) Act 1968 in light of the proposed changes to the AWI legislation?

No

Please give reasons for your answers.:

We do not believe that the existing section 13ZA should be retained. There is sufficient concern about the nature of its indiscriminate practice, especially amongst individuals with a learning disability, to suggest that it should be removed. We believe the proposed changes should replace it.

Chapter 11 - Advance directives

Should there be clear legislative provision for advance directives in Scotland or should we continue to rely on common law and the principles of the AWI Act to ensure views are taken account of?

Yes

Please give reasons for your answer.:

Scottish Care supports the continued development and use of Anticipatory Care Planning and Advanced Directives. It is important in general that individuals take responsibility for their own care and treatment especially in situations where they might become incapacitated. It is to the benefit of the individual, family members and professionals involved in care and treatment that there is a robust understanding of an individual's expressed wishes and desires. The principles of the AWI Act would enable their appropriate use and sufficiency of safeguards to ensure that the autonomy and wishes of the individual are upheld at all points, enabling alteration of opinion or perspective.

If we do make legislative provision for advance directives, is the AWI Act the appropriate place?

Yes

Please give reasons for your answers.:

We believe the AWI Act is the right place to enable legislative provision. Our only concern is that the use of Advance Directives would only be perceived as necessary in situations where incapacity was proven as this might preclude their use in end of life and last day palliative contexts. Providing there was appropriate public awareness and education we believe that the AWI and its human rights based principles would be an appropriate location for such provision.

Chapter 12 - Adjustments to authorisation for medical treatment

Do you agree that the existing s.47 should be enhanced and integrated into a single form?

Yes

Please give reasons for your answer.:

Do you think that there should be provision to authorise the removal of a person to hospital for the treatment of a physical illness or diagnostic tests?

Yes

Please give reasons for your answer.:

We agree with this providing there was assurance that the best interests of the individual were always delineated and articulated.

Do you agree that a 2nd opinion (medical practitioner) should be involved in the authorisation process?

Yes

No

Please give reasons for your answer.:

We believe that regardless of dispute from family that an extended safeguard would be assured by a second medical practitioner giving authorisation.

Do you agree that there should be a review process every 28 days to ensure that the patient still needs to be detained under the new provisions?

Yes

How many reviews do you think would be reasonable?:

It is important that the review is timely and agreed but equally that there should be no presumption that the provisions cannot be altered within those 28 days.

Do you think the certificate should provide for an end date which allows an adult to leave the hospital after treatment for a physical illness has ended?

Yes

Please give reasons for your answer.:

As above.

In chapter 6 we have asked if we should give consideration to extending the range of professionals who can carry out capacity assessments for the purpose of guardianship orders. Section 47 currently authorises medical practitioners, dental practitioners, ophthalmic opticians or registered nurses who are primarily responsible for medical treatment of the kind in question to certify that an adult is incapable in relation to a decision about the medical treatment in question. It also provides for regulations to prescribe other individuals who may be authorised to certify an adult incapable under this section. Do you think we should give consideration to extending further the range of professionals who can carry out capacity assessments for the purposes of authorising medical treatment?

Yes

Please give reasons for your answers.:

We would respond in similar terms to section 6.

Chapter 13 - Research

Where there is no appropriate guardian or nearest relative, should we move to a position where two doctors (perhaps the adult with incapacity's own GP and another doctor, at least one of whom must be independent of the trial) may authorise their participation, still only on the proviso that involvement in the trial stops immediately should the adult with incapacity show any sign of unwillingness or distress?

Yes

Please give reasons for your answer.:

Every care should be sought to ensure the engagement and involvement of the individual. We would suggest that there would be benefit for a non clinical personal advocate to be appointed in such circumstances and that such an independently appointed individual would have appropriate training and support to enable their role in decision making.

When drafting their power of attorney should individuals be encouraged to articulate whether they would wish to be involved in health research?

Yes

Please give reasons for your answer.:

We would suggest that individuals be encouraged to make this decision at the earliest possible stage. Such decision making requires robust information and guidance.

Should there be provision for participation in emergency research where appropriate (e.g. if the adult with incapacity has suffered from a stroke and there is a trial running which would be likely to lead to a better outcome for the patient than standard care)?

Yes

Please give reasons for your answer.:

We would suggest a degree of independence is necessary through the role of a non clinical personal advocate as above.

Should authorisation be broadened to allow studies to include both adults with incapacity and adults with capacity in certain circumstances?

Yes

Please give reasons for your answer.:

Should clinical trials of non-medicinal products be approached in the same way as clinical trials of medicinal products?

Yes

Please give reasons for your answer.:

We see no difference in potential impact upon the individual.

Should there be a second committee in Scotland who are able to share the workload and allow for appeals to be heard respectively by the other committee?

Yes

Please give reasons for your answer.:

We believe that the current process to be overly burdensome on the existing committee.

Should part 5 of the act be made less restrictive?

Yes

Please give reasons for your answer. :

For the benefit of the avoidance of conflict of interest.

Miscellaneous Matters

Are there any other matters within the Adults with Incapacity legislation that you feel would benefit from review or change?

No

Please give reasons for any suggestions.:

About you

What is your name?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Care

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very dissatisfied

Please enter comments here.:

Far too long and inaccessible to most. Does not encourage meaningful engagement with consultation.

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.: