



**The Health and  
Social Care  
Alliance  
Scotland  
(the ALLIANCE)**



**Adults with Incapacity Amendment Act  
– ALLIANCE response**

**17 October 2024**

## Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the Adults with Incapacity Amendment Act (the AWI Amendment Act) consultation.

We consider this a valuable opportunity to comment on the proposals and the importance of reform to mental health legislation. It is positive that the proposals align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRC) and incorporate some of the recommendations of the Scottish Mental Health Law Review (SMHLR).

However, whilst we acknowledge the fact that the Scottish Government have stated that this is an initial step towards longer term and larger changes in the law, we do not think that the proposed amendments go far enough to truly introduce positive change for people subject to the Act.

The ALLIANCE have concerns about the amendments approach being taken. Instead, we recommend that the Scottish Government legislate for a rights based system of supported decision making that will replace guardianship and which is in line with the UNCRC. We do not believe that the proposed new principles can be fully realised without a new supported decision making framework that is robustly resourced, implemented and independently scrutinised to support them.

## Part 1: Principles of the legislation

**Question 1: Do you agree that the principles of the AWI Act should be updated to require all practicable steps to be taken to ascertain the**



## **will and preferences of the adult before any action is taken under the AWI Act?**

**Yes.**

The ALLIANCE is encouraged to see that the proposed principles of the AWI Act reflect the recommendations contained within the Scottish Mental Health Law Review (SMLHR) and the UN Convention on the Rights of People with Disabilities (UNCRPD), as we have stated in our previous consultation response to the Adults with Incapacity Act<sup>1</sup>. The ALLIANCE strongly supports taking forward the SMHLR recommendation drawn from the Three Jurisdictions Report to give greater priority to the will and preferences of the adult<sup>2</sup>.

While it is true that the intent of the AWI Act is that it should only be used when no other supportive measures have been successful, this is not the way that it has been used in practice<sup>3</sup>. For example, recent figures published by the Mental Welfare Commission for Scotland (MWC) show that 19,078 Scots were living with a welfare guardianship order in March 2024, the highest level recorded, and a 6.9% increase on 2023. While the increase is similar to previous years, the number of existing guardianship orders has more than doubled in the last 10 years<sup>4</sup>.

We also believe that aligning the AWI Act with Article 12 of the UNCRPD will contribute to ensuring that people's human rights are respected, protected and fulfilled<sup>5</sup>.

A way to achieve this is by taking 'all practicable help and support to enable the adult to make their own decisions about matters should have been given and shown to have been given without success' prior to an intervention under the Act<sup>6</sup>.

For clarity, the AWI Act and accompanying guidance should define the practicable steps and explain how to utilise these steps to ascertain someone's will and preference. For example, one of the most effective



ways to ensure that ‘practicable steps’ are taken to ascertain will and preferences is increasing awareness of and access to independent advocacy. Independent advocacy must be recognised for its crucial role in providing supported decision making<sup>7</sup>. We elaborate on this in answer to question 4.

Although UNCRPD rights are not legally enforceable in Scotland and Scots Law, the United Kingdom is a state party to international obligations. Whilst the proposed reforms may get closer to the requirements of the UNCRPD, much wider and more substantive reform will be necessary to achieve full compliance. Substantive reforms should and could include taking forward the Human Rights Bill and the more radical reforms recommended by the SMHLR, such as giving proper effect to the economic, social and cultural rights of disabled people, stronger safeguards and better accountability where people are subject to involuntary care.

**Question 2: Do you agree that in the AWI Act we should talk about finding out what that adult’s will and preferences are instead of their wishes and feelings?**

**Yes.**

The AWI Act should be aligned with the UNCRPD and the language of human rights<sup>8</sup>. By amending the Act in this way, there would be additional safeguards to ensure that human rights are centred in every decision related to the Act, with people’s will and preferences being respected<sup>9</sup>.

According to the UNCRPD Article 12(4), “States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances,



apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body”<sup>10</sup>.

Ultimately, the legislation requires people deemed as “incapable” to be treated on an equal basis as anyone else under the law. The ALLIANCE supports all measures that place a duty on finding out an individual’s will and preferences as a step to strengthening legal capacity, as per the recommendations of the Independent Review of Learning Disability and Autism in the Mental Health Act (the Rome Review)<sup>11</sup>.

With the appropriate support, disabled people are able to express their will and preferences. Where a person has difficulty in communicating this directly, the UN Committee on the Rights of Persons with states that one should achieve a “best interpretation” of the person's “will and preferences”, involving those who know the person<sup>12</sup>.

The ALLIANCE support measures that place emphasis on finding out the individual’s will and preferences and puts them at the heart of the decision making process, as a practical step in strengthening the right to legal capacity. It is important that reasons are clearly explained for decisions taken that conflict with an individual’s expressed will and preference, and that there is independent scrutiny of these decisions. This will help to embed consideration of the impact on rights into practice.

In situations where the individual’s will and preferences are not known, in a crisis, or where will and preference appear to conflict, supported decision making becomes all the more important and requires additional efforts. This may result in a “best interpretation of will and preference” based on what is known of the individual and their wishes. We elaborate on supported decision making in answer to question 4.



**Question 3: Do you agree that any intervention under the AWI Act should be in accordance with the adult's rights, will and preferences unless not to do so would be impossible in reality?**

**Yes.**

Any and all interventions under the AWI Act must be in accordance with the adult's rights, will and preferences in line with the UNCRPD.

While the ALLIANCE understands that in some circumstances there will be a need to circumvent someone's rights, will and preferences to protect themselves and others (for example, in relation to limited and qualified rights), clarification is needed on the meaning of the wording 'impossible in reality'. Our member, the Scottish Commission for People with Learning Disabilities (SCLD) recommends exercising caution when addressing this wording and that each person's individual support needs, circumstances and disabilities should be fully taken into account.

The ALLIANCE strongly recommends that both a clear definition and guidelines are developed for 'impossible in reality'. Without a clearly understood definition, 'impossible in reality' is open to subjective interpretation that could mean people's independence, choice, control and liberty are unfairly and unnecessarily taken away from them.

Our member, People First Scotland, also note that all people communicate, in one way or another. Where an individual's communication is extremely limited, it is up to the supporter to interpret the will and preference of the person based on the relationship they have with the decisionmaker and everything they know about their life<sup>13</sup>.

**Question 4: Do you agree that the principles should be amended to provide that all support to enable a person to make their own**



## **decisions should be given, and shown to have been unsuccessful, before interventions can be made under the AWI Act?**

**Yes.**

The ALLIANCE agrees with the proposed amendments to the principles. Fundamentally, we believe the legislation must be framed as law that exists to provide support to individuals whose capacity may be limited, rather than to remove capacity from them. Currently, the AWI Act is framed in a way that presumes incapacity rather than capacity.

The UNCRPD Committee’s General Comment No. 1 states that countries signed up to the UNCRPD “must review the laws allowing for guardianship... and take action to develop laws and policies replacing substitute decision making with supported decision making, which respects the person’s autonomy, will and preferences”<sup>14</sup>. This confirms that substitute decision making is fundamentally incompatible with the human rights legislation.

Although the ALLIANCE supports the proposal to amend the principles, we recommend that care consideration is given to the term ‘unsuccessful’. Unless properly defined and accompanied by guidance, this term could be subjectively interpreted and lead to inconsistent approaches to interventions where people who could have been supported to make a decision have their rights, will and preference overruled.

It is fundamental in making the shift towards a system that is fully based on supported decision making that, in all instances, all efforts are directed towards enabling the individual to express their “will and preferences” and make a decision before any other type of intervention is considered. This must be supported by meaningful and robust obligations that can be independently scrutinised.

Supported decision making may, at times, require what might be considered “100% support”, based on the “best interpretation of will and



preferences”. However, it is crucial that this is always conceived of as ‘support’, given the imperative to move away from a system in which a person’s legal capacity can be restricted by legislation.

Overall, the ALLIANCE recommends that the Scottish Government create a supported decision making framework, co-produced by people with lived experience, their families, carers, trusted persons and the third sector, and embed this into legislation.

There is also a need to focus on using supported decision making mechanisms to facilitate early intervention and prevention. ALLIANCE members and partners have noted that by the time people reach states of distress or crisis, it can often be too late to ensure respect for their rights, will and preferences. This issue was raised specifically in relation to older people and those with dementia. A proactive approach to securing early and preventative support is needed, rather than only taking place at times of crisis or retrospectively.

The United Nations Handbook for Parliamentarians states: “With supported decision making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when the person with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual”<sup>15</sup>.

As noted in our reponse to question 4, ALLIANCE member People First Scotland has commented that all people communicate, in one way or another. Where communication is extremely limited, it is up to a skilled supporter to interpret the will and preference of the person based on the relationship they have with the decision maker and everything they know about their life. They have set out a range of considerations and ways in which people can be supported with decision making <sup>16</sup>.





People participating in a supported decision making process must be at the centre of their own decision making. It is essential that whoever is providing support to the decision maker helps them to consider all options available to them. The support given must meet the following criteria:

- Support is made available to enable the person to make decisions
- Support is tailored to the person and their situation
- Support varies in type and intensity depending on the type of decision
- Supporters enable the person to exercise choice and control based on the person's will and preference
- A person's legal capacity is not questioned because by definition it cannot be removed

As stated in the UNCRPD Committee's General Comment No. 1 all forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in their objective best interests<sup>17</sup>.

All forms of support that are provided should be monitored to evaluate effectiveness and use. This would enable the sharing of good practice and outcomes. Understanding what works and what needs to be improved would lead to more successful than unsuccessful interventions.

**Question 5: Do you agree that these principles should have precedence over the rest of the principles in the AWI Act?**

**Yes.**

There is currently no hierarchy within the current principles. This means that people's wishes and feelings have to compete with the other principles. Priority in the AWI Act should be given to an assumption of capacity and giving full effect to an individual's rights, will and preferences so that they cannot be overridden and are embedded into each decision.

As indicated in the previous answer, as well as giving precedence to a person's rights, will and preference, people must be empowered and



enabled to make their own choices through a supported decision making framework. Efforts must also be made to create, implement and independently scrutinise interventions made under the AWI Act.

**Question 6: Do you have any suggestions for additional steps that could be put in place to ensure the principles of the AWI Act are followed in relation to any intervention under the Act?**

**Yes.**

More detail is needed, particularly in relation to monitoring and evaluation of the AWI Act. Accountability and transparency are key human rights principles. More robust monitoring and evaluation would enable better understanding of how the law is being used and inform any future improvements needed to implementation of the Act and the principles.

There is also a need to improve data collection and monitoring on the use of coercive interventions to understand how often coercion is being used, and why. This should include qualitative data collection to understand people's direct experiences.

The ALLIANCE also recommends following the Scottish Independent Advocacy Alliance's (SIAA) five key steps<sup>18</sup>. These steps are:

1. Include an explicit right of access to independent advocacy for people under the updated AWI Act.
2. Use guidance to adopt an 'opt-out' signposting pathway for independent advocacy provided in connection with the Act.
3. Adopt the definition of independent advocacy agreed by SIAA members and include it in the Act and guidance.
4. Increase understanding of independent advocacy as a supported decision making tool.
5. Sustainably increase provision of and resourcing for independent advocacy organisations.



**Question 7: Do you agree with the change of name for attorneys with financial authority only? Please add any comments you have around this.**

**No.**

The ALLIANCE does not believe that the change of name for attorneys with financial authority only will make significant changes to the system or any substantive difference to the impact of the role on people. Although we do not think such a change will have dramatic negative consequences, any changes made must be communicated accessibly, with accompanying guidance to avoid adding unnecessary confusion to an already complex system.

**Question 8: Do you agree with our proposals to extend the power of direction of the sheriff?**

**Yes.**

The ALLIANCE believes that by extending the power of direction of the sheriff, there would be an additional safeguard for people under guardianship or power of attorney checking that their rights, will and preferences are being appropriately acted upon.

However, if the power of the Sheriff Court is extended, the system would need to evolve significantly, which will require additional resources and capacity to meet the needs of those subject to the legislation, whether in relation to these specific powers or more widely.

The ALLIANCE believes there should be a requirement in all these cases that the judicial authority must meet the adult to whom the application relates, including if this requires a visit to the adult. Article 13 of the UNCRPD requires that “procedural accommodations” are provided to facilitate the effective role of participants with disabilities, and we agree that



the focus on flexible options for the participation of the adult are increasingly required. We understand that the procedural rules in Germany's courts require personal contact with the adult which, in practice, encourages the frequent participation of the adult.

Enhanced support and training is needed for judicial decision makers - including in relation to the UNCRPD, human rights and supported decision making - to ensure that people are able to participate meaningfully in concern and complaints procedures, and that systems are person centred and rights based.

Further, Article 13 of the UNCRPD requires “appropriate training to ensure effective access to justice” and we agree that it will be essential for all judicial decision makers to receive comprehensive training in relation to the UNCRPD<sup>19</sup>. This should result in a robust understanding of supported decision making.

**Question 9: Do you agree with our proposal to amend the powers of investigation of the OPG to enable, where appropriate, an investigation to be continued after the death of the adult?**

**Yes.**

The ALLIANCE supports this proposal in the interests of justice, and closure for those closest to the adult. We agree with the Office of the Public Guardian (OPG) that this would also minimise the risk of misappropriation of funds in an adult's estate, and the risk to other adults who may be at risk. The function and remit for investigations should be laid out within the legislation and linked to human rights standards.

**Question 10: Do you agree that the investigatory responsibility between OPG and local authority should be split in the manner outlined above?**

**No.**



We believe that this proposal requires further consideration. If investigations and monitoring are to be in part the responsibility of local authorities, the ALLIANCE and its members are concerned that this could create a conflict of interest as local authorities can have responsibility for welfare guardianships. We recommend that investigatory responsibility is held by an independent body without responsibility for guardianships.

**Question 11: Will these changes provide greater clarity on the investigatory functions of OPG and local authority?**

**No.**

We believe that this proposal requires further consideration. Please see our answer to question 10 for details on this.

**Question 12: Will this new structure improve the reporting of concerns?**

**No.**

In addition to our concerns raised in answer to question 10, further clarity is needed on the monitoring of reporting concerns and who will be responsible for actioning these.

**Part 2: Powers of attorney**

**Question 13: Do you agree with the proposals for training for attorneys?**

**Yes.**

The ALLIANCE believes that training is one necessary tool for those with the power to declare incapacity to improve knowledge, awareness and processes. However, due to the gravity of the decisions being made concerning people's liberty, independence, choice and control, we believe



that a short presentation is insufficient. We recommend such training should also include modules on, for example, human rights, disability, mental health, independent advocacy and inclusive communication. Training should be required before solicitors and individuals take up their role as an attorneys. The training should also be regularly reviewed.

Further consideration is also needed on who will be responsible for implementing and monitoring this training. Those responsible should ensure that the training is inclusive and accessible so anyone can access it if they choose to, and it does not put people off completing it. ALLIANCE member, Age Scotland, also note that if the training is online, consideration must be made for people who are digitally excluded. This means consideration must be given to providing alternative, in-person training.

The UNCRPD Committee General Comment No.1 supports both trusted support persons and advance planning measures, and the ALLIANCE believes that attorneys remain a worthwhile mechanism for facilitating this<sup>20</sup>. We agree that the attorney's role needs to be clearly centred around supporting the rights, will and preference of the individual.

The ALLIANCE does have concerns about the expectations on lay attorneys to be able to carry out the training, as well as their overall role as an attorney<sup>21</sup>. Significant support and guidance may be necessary for some lay attorneys, both before taking on the role and while performing it.

**Question 14: Do you agree that OPG should be given power to call for capacity evidence and defer registration of a power of attorney where there is dispute about the possible competency of a power of attorney document?**

**Yes.**

While there should always be a presumption of an individual's capacity, the ALLIANCE agrees that current and future POAs should be regularly reviewed once registered. We agree that there should be a power to refuse



registration and enquire for more evidence to safeguard a person and their property. To prevent issues with documentation, accessible guidelines should be developed to demonstrate the quality of evidence required for registration. If registration is denied then this and the reasons for referral should be recorded and accessible to the OPG and others reviewing future registration.

**Question 15: Do you agree that OPG should be able to request further information on capacity evidence to satisfy themselves that the revocation process has been properly met?**

**Yes.**

As noted in our answer to question 14, the ALLIANCE believes there should always be a presumption of capacity. However, if the OPG is given the power to request further information on capacity evidence, we believe that this would add an additional safeguard to prevent someone's human rights from being infringed.

Nevertheless, we believe that the need to request further evidence must be balanced with the individual's will and preference, their circumstances, and the views of the individual's trusted person. For example, if a person has a permanent and deteriorating condition such as dementia then capacity evidence is unlikely to be necessary if there has been no change or a worsening of their condition. Going through revocation and further applications may cause stress and be costly for the families, unpaid carers and trusted people of the individuals. On the other hand, if someone has a fluctuating condition, then they may want the OPG to review the evidence. Flexibility and choice must be built into the AWI Act as a result.

**Question 16: Do you agree that OPG should be given the power to determine whether they need to supervise an attorney, give directions**



**or suspend an attorney on cause shown after an investigation rather than needing a court order?**

**Yes.**

We believe that any safeguards intended to protect the will and preferences of individuals under a POA is a positive change. However, judicial oversight is also vital to ensure that the law is being followed and human rights respected. Further consideration is needed to decide what would trigger such determinations after an investigation and how attorney activities will be monitored. Additionally, if the OPG is given such powers they must have sufficient resources and capacity to take such action.

**Question 17: Should we extend the class of persons that can certify a grantor's capacity in a power of attorney?**

**Yes.**

If there is an extension to the class of persons able to certify, then the persons must be qualified and trained to do so. This is so safeguards are in place for capacity assessments. A person's rights, will and preferences must not be undermined by the need for expediency. In other words, the ALLIANCE is concerned that extending the class of persons able to certify could simply extend the issues of people's human rights being breached and delays within the system if appropriate safeguards are not also put in place and the systems is not adequately resourced.

**Question 18: Do you agree that a paralegal should be able to certify a grantor's capacity in a power of attorney?**

**Yes.**

Please see our answer to question 17.





**Question 19: Do you agree that a clinical psychologist should be able to certify a granter's capacity in a power of attorney?**

**Yes.**

We think that clinical psychologists have the required knowledge, skills and training to certify a granter's capacity in a POA and are potentially more qualified to do so than a paralegal. Please see our answer to question 17.

**Question 21: Do you agree that attorney's, interveners and withdrawers (under Part 3) should have to comply with an order or demand made OPG in relation to property and financial affairs in the same way as guardians?**

**Yes.**

We believe that any safeguards intended to protect the rights, will and preferences of individuals subject to the AWI Act are a positive step. However, we believe that judicial oversight is also vital to ensure that the law is being followed and human rights respected. Further consideration is needed to decide what would trigger such an order or demand and how attorney, interveners and withdrawer activities will be monitored. Additionally, if the OPG is given such powers they must have sufficient resources and capacity to take such action.

**Question 22: Do you agree that the Public Guardian should have broader powers to suspend powers granted to proxy under the AWI Act whilst an investigation is undertaken into property and financial affairs?**

**Yes.**

The ALLIANCE and our members find the mechanism of proxy decision makers concerning. Key to this system is the individual's involvement, choice, rights, will and preference in picking their trusted person. Such lack of involvement in choosing the proxy representative does not reflect a



human rights based approach and does not prioritise the will and preference of the individual. Additionally, there is the likelihood that due to the less thorough process in the selection of a proxy, there would be fewer safeguards around protecting an individual's rights, will and preference.

However if this proposal is put into legislation, we believe that it could provide an additional safeguard and oversight protecting an individual's property and financial affairs. Before this is done, however, further consideration is required on how proxy's and their actions will be monitored and whether the OPG will receive further funding to carry this additional monitoring out.

**Question 23: Do you agree that the MWC and local authority should have broader powers to suspend powers granted to a proxy under the AWI Act whilst they undertake an investigation into welfare affairs?**

**No.**

Whilst we support strengthening accountability measures through the MWC, the ALLIANCE does not consider it appropriate for the local authority to be involved in investigating welfare affairs and this proposal requires further consideration.

If investigations are to be in part the responsibility of local authorities, the ALLIANCE are concerned that this could create a conflict of interest because local authorities can also have responsibility for welfare guardianships. We recommend that investigatory responsibility is held by an independent body without responsibility for guardianships.

Please also see our answer to question 22 for further elaboration on the proxy mechanism.



## **Part 4: Management of Resident's Finances**

**Question 35: Do you think that alternative mechanisms like the ATF scheme, guardianships and intervention orders adequately address the financial needs of adults with incapacity living in residential care settings and hospitals?**

**No.**

The ALLIANCE would emphasise the need for a human rights based and supported decision making approach to underpin the alternative mechanisms that are used to address financial needs of adults with incapacity living in residential care settings and hospitals. There are many power imbalances that will exist in residential care settings and hospitals so ensuring support decision making is well understood by professionals in these settings is important.

## **Part 5: Changes to s.47 certificates and associated matters**

**Question 36: Do you agree that the existing section 47 certificate should be adapted to allow for the removal of an adult to hospital for the treatment of a physical illness or diagnostic test where they appear to be unable to consent to admission?**

**No.**

The ALLIANCE believes that this proposal could potentially conflict with the principles of the legislation and supported decision making. We recognise that in emergency situations consent of the individual may be difficult to gain and treatment may be done in cases of necessity but, as stated in our answer to question 1, all practicable steps should be taken to understand the rights, will and preference of the individual which should also involve their family, unpaid carers and trusted persons.

The SMLHR found evidence of poor practice whereby people in care homes were being said to lack capacity - with care home staff thinking that



they had guardianship-like powers - and being removed to hospital without their consent, despite having capacity<sup>22</sup>. Accessible guidance must accompany the Act once enacted directed towards health and social care staff that clarifies their remit and responsibilities under it.

If this proposal is taken forward, there must be the right to appeal, complain and challenge included with immediate and automatic effect, with an opt-out independent advocacy referral. There must also be clarity on when removal will be permitted, and for what treatment and tests. All steps should be taken to reduce someone's hospital stay to mitigate the risk of delayed discharge and detention.

**Question 37: Do you consider anyone other than GPs, community nurses and paramedics being able to authorize a person to be conveyed to hospital? If so, who?**

**Yes.**

Any decisions on the conveyance of a person to hospital should be with the prioritisation of the individual, their family and unpaid carers, or trusted individual input so that the authorisation reflects their rights, will and preference.

If authorisation were extended to other categories of professionals, medical or otherwise, they must be appropriately trained and qualified to be able to assess the situation and make such a decision.

**Question 38: Do you agree that if the adult contests their stay after arriving in hospital that they should be assisted to appeal this?**

**Yes.**

The ALLIANCE welcomes the proposal to make the current processes to raise a concern or complaint more accessible, equitable, co-ordinated, and effective. Accountability is a core human rights principle, and robust



oversight is needed to implement effective safeguards against arbitrary decisions and strong accountability mechanisms to provide prompt redress for people if things go wrong.

People can experience lengthy waiting times if they wish to complain or review decisions. This can have a significant impact on individual rights and on care and treatment. ALLIANCE members and partners noted that it is currently very difficult to appeal against a medical decision, and that the burden is on the person receiving care and treatment – and their unpaid carers – to appeal, which can be challenging.

ALLIANCE members welcomed the proposal to take a person centred approach to concern and complaints procedures, which are designed around the needs of the complainant. Everyone has the right to participate in decisions that affect their lives and rights. Participation must be active, free, meaningful, and give attention to issues of accessibility and inclusivity, including access to information in a format and language which can be understood. There should be a clear requirement to facilitate personal participation, to record how this has been done, and in the absence of participation to record the reasons and to record the steps taken to ascertain the rights, will and preferences of the adult.

As answered in previous questions, ensuring opt-out referral to independent advocacy is made in these instances would support taking a human rights based approach.

At present, section 47 certificates can effectively exclude the adult's views if they are deemed to be incapable. We also consider that a short appeal period should be allowed to elapse before treatment can take place.

### **Question 39: Who could be responsible for assisting the adult in appealing this in hospital?**

Alongside advance statements, independent advocacy plays an important role in supporting the exercise of legal capacity and enabling supported



decision making. Our member SIAA recommends that an independent advocacy worker would not be responsible for the appeal, however there should be an opt-out referral to independent advocacy and clear explanation to the person about what independent advocacy is, where possible from the independent advocacy organisation themselves. We believe that further consideration of the resourcing of independent advocacy providers is required, to enable this role to be carried within a climate of increasing demand.

**Question 40: Do you agree that the lead medical practitioner responsible for authorising the section 47 certificate can also then authorise measures to prevent the adult from leaving the hospital?**

**No.**

It is not clear whether s.47 will allow for people to be detained, or simply treated in hospital. This raises concerns for the ALLIANCE and our members as this may lead to instances of deprivation of liberty.

We consider that anyone authorising a section 47 certificate must have undertaken sufficient training akin to the requirements contained within the Mental Health Act<sup>23</sup>. If such measures are medical, then those qualified should be responsible for ensuring treatment for the adult, taking into account the rights, will and preference of the adult in question, their families and unpaid carers.

As stated in section 50 of the AWI Act, people can be helped if in serious suffering. In these instances, there must be clarity on what is meant by 'serious suffering'. Alongside this, consideration must be given to people's rights to religion and to culture. For example, if an individual who is a Jehovah's Witness refuses a blood transfusion, then such an intervention is clearly against their will and preference.



**Question 41: 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.**

The emergency processes which are triggered by a section 47 certificate should only last as long as the emergency. If there are dates set, then there are potential implications of deprivation of liberty if a person is detained or prevented from leaving hospital beyond this.

**Question 42: Do you think that there should be a second medical practitioner (i.e. one that has not certified the section 47 certificate treatment) authorising the measures to prevent an adult from leaving the hospital?**

**No.**

As stated in our answer to question 40, although this has the potential to act as a safeguard, it is not clear whether section 47 will allow for people to be detained, or simply treated in hospital. This raises concerns for the ALLIANCE and our members as this may lead to instances of deprivation of liberty due to the lack of necessity.

If a second medical practitioner is permitted to prevent someone from leaving hospital then there must be a short period of review put in place, with immediate and automatic access to appeal and judicial oversight within a short time frame of a maximum of 72 hours. In such instances, the will and preference of the adult in question, their families, carers and trusted persons must be taken into account and prioritised.

**Question 43: If yes, should they only be involved if relevant others such as family, guardian or attorney dispute the placement in hospital?**

**No.**



Due to the gravity of the decision of detaining a person in hospital, seeking authority from a second independent medical practitioner may provide an appropriate safeguard to protect a person's human rights.

The family, guardian, or attorney's views (if they are the individual's trusted person) and the will and preference of the individual must be prioritised in this instance. For example, if the individual does not want to be kept in hospital or their family member feels that being prevented from leaving the hospital would be detrimental to the individual and is in contention with what they want then the medical practitioners must take this into account when making their assessment.

**Question 44: Do you agree that there should be a review process after 28 days to ensure that the patient still needs to be made subject to the restriction measures under the new provisions?**

**No.**

A time period of 28 days is too long for a person to wait and be detained for review. The review process should begin immediately or for a maximum of 72 hours if the person, their families, unpaid carers or trusted persons disputes the restrictions put in place.

As answered in our previous questions there should be an automatic and immediate right to appeal any decision made, with support from an independent advocate.

**Question 45: Do you agree that the lead clinician can only authorise renewal after review up to maximum of 3 months before Sheriff Court needs to be involved in review of the detention?**

**No.**

Please see our answer to question 44.





**Question 46: What sort of support should be provided to enable the adult to appeal treatment and restriction measures?**

The ALLIANCE strongly agrees that an adult should be enabled, supported and empowered to appeal any restriction or detention measure.

Anyone subject to a treatment and restriction measure should be involved in the appeal process and be consulted with whoever is conducting the appeal to ensure that their rights, will and preferences are heard and adhered to.

A vital aspect to being heard is being able to communicate in the way that suits and works for the individual. Appeals should have a duty to accommodate inclusive communication and accessible information methods tailored to each individual.

The ability and right to appeal, complain and challenge any treatment and restriction measure in a human rights necessity. In the case of *Aberdeenshire Council v SF*, it was found that the European Convention on Human Rights (ECHR) was being breached because there was no route to challenge, which was incompatible with article 5<sup>24</sup>.

Alongside this, a right to independent advocacy should be incorporated within the legislation, which should be immediately and automatically triggered when a restriction or detention measure is put in place. Ensuring an opt-out referral to independent advocacy is made in these circumstances would support taking a human rights based approach.

**Question 47: Do you agree that section 50(7) should be amended to allow treatment to alleviate serious suffering on the part of the patient?**

**No.**



As stated in our answer to question 40, in these instances, there must be clarity on what is meant by 'serious suffering'. This may be subjective depending on individual circumstances, will and preference. For example, consideration must be made to those undergoing end of life care whereby treatment would currently only be directed towards pain relief.

Alongside this, consideration must be given to people's rights to religion and to culture. For example, if an individual who is a Jehovah's Witness refuses a blood transfusion, then such an intervention is clearly against their will and preference.

If care is refused or treatment disputed by a family member, guardian or POA refuses or disputes treatment, it should only be given on an emergency basis.

**Question 48: Would this provide clarity in the legislation for medical practitioners?**

**No.**

Please see our answer to question 47.

**Part 6: Changes to guardianship, interim guardianship and intervention orders**

**Question 49: Do you think the requirement for medical reports for guardianship order should change to a single medical report?**

**No.**

As a broader point before moving on to answer this specific question, the ALLIANCE note that we have concerns about the amendments approach being taken. Instead, we recommend that the Scottish Government legislate for a rights based system of supported decision making that will replace guardianship and which is in line with the UNCRPD. We do not believe that the proposed new principles can be fully realised without a new



supported decision making framework that is robustly resourced, implemented and independently scrutinised to support them.

However, if these proposals for amendments move forward as a step towards longer term and more significant reform, the ALLIANCE understands that there are significant pressures and delays in relation to guardianship orders and that a way to mediate this would be to reduce bureaucracy. We do not agree that the requirement for medical reports for guardianship order should change to a single medical report. Condensing the reports into a single medical report runs the risk of favouring expediency and efficiency over safeguards and due diligence.

If the decision is made to reduce the reports required for guardianship orders, and therefore there will be fewer safeguards are in place, then the person carrying out the report should be adequately qualified for the role.

**Question 50: Do you agree with our suggestion that clinical psychologists should be added to the category of professional who can provide these reports (where the incapacity arises by reason of mental disorder)?**

**Yes.**

If any additions are made to the category of professionals who can provide these reports, then the professional must be adequately qualified to assess capacity, trained in the process and resourced sufficiently. Clinical psychologists are trained in a wide range of psychological difficulties however assumptions must be not made on their level of knowledge and awareness of human rights and disabilities, profound and multiple learning disabilities, dementia etc. Sufficient training must be provided if there are gaps in skills and knowledge.



**Question 51: Do you think the Mental Health Officer form for guardianships can be improved, to make it more concise whilst retaining the same information?**

**Yes.**

It is already well known the Mental Health Officer (MHO) services are facing pressure in meeting the expectations of the Mental Health (Care and Treatment) (MHCT) Act and the AWI Act<sup>25</sup>. MHOs perform a vital role in providing safeguards in respect of the right of individuals subject to the Act.

Whilst we believe that action is required to alleviate this pressure, such as focusing on care planning and reducing unnecessary court applications, MHO work must be resourced and funded well enough so that the role can focus on ensuring the best care arrangements for individuals whilst also recording enough detailed information.

The MHO form is a necessary safeguard to ensure that people are receiving the right care. The form itself should be as accessible, following inclusive communication principles, avoid unnecessary legal jargon, and be made available in multiple formats and languages.

**Question 52: Do you think the ‘person with sufficient knowledge’ form can be improved, making it more concise whilst retaining the same information?**

**Yes.**

The ALLIANCE believes that all forms of communication should be provided in accessible and multiple formats and languages, including augmentative and alternative communication, to allow all parties involved to understand it fully. In However, making the document accessible however does not mean that it should miss out critical information.



**Question 53: Should the person with sufficient knowledge continue to be the person who prepares the report for financial and property guardianship?**

**Yes.**

The ALLIANCE supports this proposal, which will allow for consistency and prevent confusion. The person with sufficient knowledge must be able to know the individual well enough to reflect their will and preferences. The form itself must be provided in an accessible format so that anyone is able to understand and fill it in if supporting someone.

**Question 54: Do you agree with our proposal to replace the second part of the ‘person with sufficient knowledge’ report with a statutory requirement to complete the OPG guardian declaration form?**

**Yes.**

We believe that the OPG guardian declaration form will provide further safeguards to people’s financial matters as it is more detailed. However, if this proposal is taken forward, the change must be widely and inclusively communicated and shared. Additionally, if the form itself requires more information than the original ‘person with sufficient knowledge’ report then the form should be formatted accessibly, without unnecessary jargon, and the implications of filling it in clearly explained.

**Question 55: Should sheriffs be afforded the same discretion with Mental Health Officer report timings as they are with medical reports?**

**Yes.**

Sheriffs should be afforded the same discretion with timings. With such discretion there must be checks put in place to ensure that the individual’s circumstances haven’t changed. However, further consideration is required to assess whether this will have a positive or negative impact on delays



within the system and the resources required to mitigate any exacerbation of application delays.

**Question 56: Do you agree that the best approach to cater for urgent situations is to amend the existing interim guardianship orders?**

**No.**

In catering for urgent situations, every possible effort must be made to ensure that an order meets the rights, will and preference of the individual in question. This would include involving the person's family, friends and unpaid carers if they were designated as trusted persons able to reflect their will and preference.

Where possible, we believe that a hearing should be held to consider the interim order and its necessity. The urgency for an interim guardianship order must be balanced against human rights especially if deprivation of liberty is being suggested and is against the individual's will and preference.

Any order should be time limited, with a short term date for review set to avoid any detention. The individual subject to the placement must be involved at each stage to make sure their will and preferences are being adhered to.

Interim guardianship orders are particularly difficult to challenge especially when someone is being moved from place to place. There should instead be an automatic right of appeal triggered when an order is made. When triggered an independent advocate should be appointed automatically as in the MHCT Act to ensure that a person has all the support they need and to ensure that their rights are met<sup>26</sup>. To accomplish this, sufficient resourcing and staffing would need to be available. This could be achieved in a similar vein to the advocacy service that was legislated for in the Social Security (Scotland) Act<sup>27</sup>.



**Question 57: Do you agree that an abbreviated mental health officer report together with a single medical report should suffice for a guardianship order to be accepted by the court?**

**No.**

Whilst the report could be edited for succinctness, it should not impact the quality of information provided. Any changes made to the reports should be approved by the lawful authority and audited by the MWC to ensure that information collected is sufficient. In addition, consultation should also be made by the court system to understand what changes and abbreviations would be accepted.

**Question 58: Do you agree that there should be a short statutory timescale for the court to consider urgent interim applications of this sort?**

**No.**

Whilst five calendar days would improve efficiency in urgent situations, we believe that a longer period may be needed to decide on interim powers, considering the principles of the Act and the individual's circumstances. We recommend that this proposal be amended for flexibility so that the sheriff should begin considering the application within five days but follow due process to take the time to consider each individual's case and what they would want to happen.

Further, three months, with a possibility of a six-month extension, is a significant period especially if the order is not in line with someone's will and preference. We believe that each individual's circumstances should also be taken into account as to whether a longer or shorter period should be adhered to.



**Question 59: Do you agree that further medical reports are not required when varying a guardianship to add either welfare or financial powers?**

**No.**

The ALLIANCE believes that the reports are a necessary safeguard to protect people's rights, will and preferences. For instance, whilst someone may need support to look after their finances, they may not require support for their welfare needs. In removing this requirement, there is a presumption of incapacity and a removal of an essential safeguard. The legislation must be able to accommodate flexibility and choice.

**Question 60: Does the current approach to length of guardianship orders provide sufficient safeguards for the adult?**

**No.**

All guardianships should be regularly reviewed by the appropriate authority and subject to judicial scrutiny where necessary. As in the case of *Aberdeenshire Council v SF*, where it was found that an indefinite guardianship order was found to be in breach of article 5(4) of ECHR and the Human Rights Act, the individual must have an opportunity to be heard and/or opportunity to be supported to share their views on any order so that it can be appealed, revoked or amended.

We understand that in some circumstances an indefinite order may be the right decision for some due to, for example, long term conditions such as dementia. However, with such an order there should still be regular review decided upon with the individual and trusted persons involved in each case. There should also be the option for individual, their family, carers and their trusted persons to request for a review of the order in the interim if anything changes.





Please see our answer to question 61 for further elaboration on necessary safeguards.

**Question 61: Do changes require to be made to ensure an appropriate level of scrutiny for each guardianship order?**

**Yes.**

Echoing SIAA, we urge the Scottish Government to carefully consider where opt-out independent advocacy referrals should happen within guardianships. Considering the increase in guardianships over the last decade there needs to be clearer routes to accessing independent advocacy, including non-instructed advocacy. This must be accompanied by more funding for independent advocacy organisations to respond to increased need for enabling supported decision making when guardianships are used.

**Question 62: Is there a need to remove discretion from the sheriff to grant indefinite guardianships?**

**No.**

Whilst the ALLIANCE favours the implementation of a UNCRPD-compliant supported decision making framework that replaces guardianship, in the interim we consider indefinite guardianships necessary for some people if they reflect reflection of the will and preference of the individual involved.

Please see our answer to question 60 for further elaboration.

**Question 63: If you consider changes are necessary, what do you suggest they would be?**

As stated in our answer to question 49, we believe the system of guardianship conflicts with the principles of the legislation and the UNCRPD. We suggest instead legislating for a full system of rights based supported decision making to replace guardianship. We do not think the



proposed new principles can be realised without a full system of supported decision making to support them.

It is important that there is not a 'one size fits all' approach to supported decision making, and that there is recognition that circumstances change between people and between situations. ALLIANCE members have commented that the growing focus on supported decision making is welcome and there is a need to further shift the focus in the law from one that can often operate in a custodial manner, with a focus on risk reduction and with very little consultation with people, unpaid carers and families.

**Question 64: We propose that the following powers should be added to the list of actions that guardians, attorneys and interveners should be expressly excluded from. Do you agree?**

**Yes - consenting to marriage or a civil partnership**

**Yes - consenting to have sexual relations**

**Yes - consenting to a decree of divorce**

**Yes - consenting to a dissolution order being made in relation to a civil partnership**

**Yes - consenting to a child being placed for adoption by an adoption agency**

**Yes - consenting to the making of an adoption order**

**Yes - voting at an election for any public office, or at a referendum**

**Yes - making a will if the adult is a trustee, executor or company director, carrying discretionary functions on behalf of them**

**Yes - giving evidence in the form of a sworn affidavit**

Carrying out these actions is vital to an individual's full enjoyment of some fundamental human rights, like the right to private and family life and the right to vote, which are found in international treaties like the ECHR, the Universal Declaration of Human Rights, the UNCRPD, and the International Covenant on Civil and Political Rights<sup>28</sup>. They are essential for full



participation in society. Where a person wants to partake in these actions all practicable steps should be taken to support them to do so.

**Question 65: Are there any other powers you think should be added to a list of exclusion?**

The ALLIANCE recommends that the exclusion list should be reviewed to ensure it reflects the rights contained within both domestic and international human rights law. According to the UNCRPD, everyone should be afforded their rights on an equal basis, without discrimination in relation to their disability<sup>29</sup>.

**Part 7: Deprivation of liberty proposals, stand-alone right of appeal, appointment of safeguarders**

**Question 66: Do you agree with the overall approach we are proposing to address DOL?**

**No.**

The ALLIANCE is encouraged to see the incorporation of the recommendations of the SMHLR within the proposal. We agree with this approach.

However, we do not agree that no judicial oversight is required even if someone with support can express their will and preference as it is an additional safeguard to ensure that there is no coercion taking place. European Convention of Human Rights (ECHR) caselaw highlights the need for sufficient safeguards against arbitrariness, including access to a judicial procedure capable of determining the lawfulness of the individual's detention, even where consent is provided by an authorised person, and periodic compulsory examination for the purpose of assessing whether an individual needs to remain in detention<sup>30</sup>.

Whenever someone is deprived of their liberty, this should be either a reflection of their will and preferences, or where it is not it is only possible a



risk exists to their or other's rights that proportionately and non-discriminatorily warrants a DOL and must be in fulfilment of the person's overall human rights, will and preference. If someone is unable to consent in the traditional manner, one cannot assume they are not objecting to the deprivation of liberty. As stated in our answer to question 1, all practicable steps must be taken to ensure that a person's rights, will and preferences are upheld. It will be essential for a clear record of the steps taken to enable the consent to be validated under scrutiny.

Where questions of DOL are concerned, article 5(4) ECHR requires a "speedy review" of the lawfulness of detention and continuing review "at regular intervals", particularly in circumstances where the grounds for detentions are susceptible to change over time<sup>31</sup>. The provision of a speedy and rights based review must be made as soon as possible, with a right for the MWC to intervene in individual cases.

As stated in our responses to previous questions, there must also be a right of appeal contained within the legislation which is triggered immediately upon an order being made. Any appeal process must be as accessible as possible, with an opt-out referral process to independent advocacy, to support those who may want it.

### **Question 67: Is there a need to consider additional safeguards for restrictions of liberty that fall short of DOL?**

**Yes.**

We recommend that a clause should be included within the Act that sets out how capacity will be assessed and how and when a deprivation of liberty should come into effect.

Any intervention that overrides a person's will and preference may be permissible but only on a non-discriminatory basis, not based on a person's disability. Whilst the UNCRPD and ECHR state that there may be



a necessity for the state to intervene to protect a person from abuse or inhuman or degrading treatment, or risks to their life, any diagnosis made should be done to determine the support and interventions that may be required for the individual, within a framework of supported decision making. This moves away from applying restrictions to supporting the person to exercise their human rights.

**Question 68: Do you agree with the proposal to have prescribed wording to enable a power of attorney to grant advance consent to a DOL ?**

**Yes.**

We agree with the prescribed wording enabling a POA to grant advance consent. We strongly agree that where an adult has previously granted advance consent for DOL and later objects to the consent, a determination must be sought from the Sheriff.

Along with the prescribed wording, we recommend that evidence granting advance consent, and the reasoning behind it, accompanies it to prove the authorisation process is followed and necessary.

**Question 69: What are your views on the issues we consider need to be included in the advance consent?**

Individuals should be able to make advance decisions in relation to arrangements which may amount to a deprivation of liberty, as an exercise of their legal capacity. This is in line with the UNCRPD Committee's General Comment No. 1 which supports advance planning measures.

For very distressing circumstances, advance consent may need to be specific for it to be valid. It is also essential that individuals truly understand what they are consenting to. This would require in-depth discussion with any person drawing up a POA and the criteria should be designed in such a way as to ensure this takes place. Similar to our points made earlier in



answer to earlier questions (e.g. questions 8 and 13), a training/education programme for solicitors practicing in this area and for individuals considering POA is necessary.

Those seeking advance consent must have the immediate right to appeal, with regular reviews put in place at time periods which they feel are appropriate.

**Question 70: What else could be done to improve the accessibility of appeals?**

Appeal processes must be accessible and inclusively communicated, for all involved, free from unnecessary legal jargon and available in multiple formats and languages. It is vital that guidance is provided for the person going through the appeal and/or seeking advance consent on what the process is and the implications of it so that they have full understanding and knowledge of what they are undergoing.

**Question 71: What support should be given to the adult to raise an appeal?**

As stated in our answer to question 61, an opt-out independent advocacy referrals should be automatically available. There needs to be clearer routes to accessing independent advocacy, including non-instructed advocacy. This must be accompanied by more funding for independent advocacy organisations to respond to increased need for enabling supported decision making at every stage of the appeals process.

**Question 72: What other views do you have on rights of appeal?**

The ability to appeal must be proactively available and the process started in a timely manner to avoid delays and chances of restricting a person's human rights. To ensure that this occurs appeal mechanisms must be funded and resourced sufficiently.



**Question 73: How can DOLs authorised by a power of attorney be appropriately reviewed?**

The best way to ensure the appropriateness of a review process is to co-produce the process and its implementation with people with lived experience, including their families, carers and trusted persons of POA, DOLs and related existing reviews. All reviews must be accessible and inclusively communicated, and tailored to each individual's support needs, rights will and preferences.

**Question 74: Do you agree with the proposal to set out the position on DOL and guardianships in the AWI Act?**

**No.**

The ALLIANCE does not agree with any power that conflicts with the principles of the legislation, the ECHR or UNCPRD.

**Question 75: In particular what are your views on the proposed timescales?**

We are concerned that welfare guardianship orders are reviewed by relevant local authorities as in certain cases there may be a conflict of interest as local authorities may be administering these. We recommend that all reviewed be independent of those administering the order.

We agree that more regular reviews are required when an adult is being deprived of their liberty. However, we feel that six months is too long a time period for someone to have their liberty removed from them especially if it is against their will and preferences. Timescales should be discussed with the individual, their family, carers and trusted persons, to reflect their will and preference.

We strongly agree that the individual, and people demonstrating an interest in the welfare of the individual should be able to request a review and it be actioned at any point in time during the placement.



**Question 76: What are your views on the proposed right of appeal?**

Accountability is a fundamental component of a system that respects, protects and fulfils human rights. Mainstreaming and embedding human rights standards within legislation, policy and practice is essential to providing accountability for those standards.

This takes account of the importance of accountability throughout the course – from ensuring involvement of people affected in decision making processes, through active monitoring of the impacts of decisions, to providing an effective remedy where rights are not being upheld.

**Question 77: What else could be done to improve the accessibility of appeals?**

For appeals to be adequate, they must be accessible, affordable, timely and effective. Amongst other things, effectiveness requires that decisions must be challengeable through a judicial procedure.

**Question 78: Do you agree with the proposal to have 6 monthly reviews of the placement carried out by local authorities?**

**No.**

Please see our answer to question 75.

**Question 80: Do you agree with our proposal for a stand-alone right of appeal against a deprivation of liberty?**

**Yes.**

As stated in answer to previous questions, we welcome the proposal for an automatic stand-alone right of appeal against a deprivation of liberty as this does not currently exist within the system. The right and its implementation





must be co-produced with people with lived experience, their families, unpaid carers and trusted persons.

**Question 81: Do you agree with our proposal to give the MWC a right to investigate DOL placements when concern is raised with them?**

**Yes.**

We believe that the MWC are well placed to investigate and monitor deprivation of liberty placements when a concern is raised to them as they have expert and existing knowledge, understanding and skills in this area. Monitoring placements would be helpful for contributing to the assessment of whether a human rights based approach is taken in practice. As with any additional actions or duties introduced by these proposals, the relevant agencies may require additional resources and capacity.

**Question 82: Do you agree with the proposals to regulate the appointment, training and remuneration of safeguarders in AWI cases?**

**Yes.**

Safeguarders must be adequately trained in legal, medical and social issues that they may come across when representing people in AWI cases. We strongly agree with the recommendations contained in the SMHLR and the consultation proposals. To remedy the issues currently being faced with the safeguarding role, the following should be actioned:

- Create a duty on safeguarders to record and report the actions and practicable steps they have taken to ascertain the rights, will and preferences of individuals
- Review guidance to ensure that there is a consistent approach to appointing safeguarders across all sheriffdoms
- Review guidance to ensure that the role of the safeguarder is unambiguous



- Create a uniform training/education programme, including modules focused on mental health law, disability, mental health, independent advocacy, human rights and inclusive communication, with a requirement that the training is completed before being accepted as a safeguarder
- Create a system of national standards for the work being done which would enable best practice to be shared across the country
- Revise the payments system for safeguarders to place it on a more equitable footing.
- Monitoring and evaluating of the safeguarding role, gathering the outcomes and feedback of the person they represent

**Question 83: Do you agree with the proposals for training and reporting duties for curators?**

**Yes.**

Please see our answer to question 82.

**Question 84: What suggestions do you have for additional support for adults with incapacity in AWI cases to improve accessibility?**

Accessible information and inclusive communication should follow the Six Principles of Inclusive Communication. This includes information and communication being made available in multiple inclusive formats like Community Languages, BSL, Braille, Moon, Easy Read, clear and large print, and paper formats. The ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communications and information provision is inclusive for all<sup>32</sup>.

Every organisation involved and their staff must ensure that different communication needs are inclusive. For example, many people use Augmentative and Alternative Communication (AAC). People who use AAC told the Scottish Government that help from specialists is invaluable, extra



time is needed as conversations may be longer, and that communication can be tiring<sup>33</sup>. To be aware of this, services must be person centred, to recognise and understand that every individual must be treated equitably.

Independent advocacy is a vital mechanism that can support people to participate in their own cases and improve accessibility overall. Please see our answer to question 6 for further detail on this.

**Question 85: Do you think there should be a specific criminal offence relating to financial abuse of an adult lacking capacity?**

**Yes.**

**Question 86: If so, should the liability be the same as for the welfare offence?**

**No.**

The courts and legal professionals are best placed to comment on the specific liability.

**Question 87: Do you have experience of adults lacking in capacity being supported in hospital, despite being deemed to be no longer in need of hospital care and treatment? What issues have arisen with this?**

**No.**

The ALLIANCE does not have direct experience of adults lacking in capacity being supported in hospital, however, some of our members do represent or work for and with people with lived experience of this issue.

Amongst their many concerns, our members note that hospitals are not always the best place to be, and the risks are particularly high for older or frailer people. It is also an inefficient use of scarce healthcare resources.



**Question 88: Do you foresee any difficulties or challenges with using care settings for those who have been determined to no longer need acute hospital care and treatment?**

**Yes.**

There is a clear concern from our members that moving and keeping people in care settings, when it is against their will and preference, is a deprivation of liberty and in conflict with the principles of the AWI Act. If a person is moved to a care setting it must reflect their intention, will and preference.

However, there are endemic examples of poor practice. The MWC found a lack of understanding of the law, lack of understanding of good practice, confusion over the nature of placements and misunderstanding over POA<sup>34</sup>. There are also issues where people are being moved to care homes without a community care assessment.

People deemed to have ‘incapacity’ should be supported by high quality services which enable them to lead the lives they want in their local area with support from family, carers and the wider community.

There is a restricted ability to challenge unlawful detainment currently as there are no ECHR safeguards related to this issue. We recommend that any move must be done with lawful authority and judicial oversight, the ability to challenge and the individual to make their case to an independent or judicial authority.

**Question 89: What safeguards should we consider to ensure that the interests and rights of the patients are protected?**

We recommend that the legislation incorporate the recommendations of the Mental Welfare Commission’s ‘Authority to Discharge’ report to make relevant improvements and implement appropriate safeguards<sup>35</sup>.



**Question 90: What issues should we consider when contemplating moving patients from an NHS acute to a community-based care settings, such as a care home?**

The ALLIANCE understands that there may be arguments suggesting that there is a better quality of life for people in freer settings. We also understand that the NHS and the legal system has faced pressures like never before. However, we have several concerns about this proposal and the effects it will have on people's liberty, choice, independence and human rights.

Firstly, in moving people from an NHS acute setting to community-based care settings, they will be moved twice rather than once which is extremely disruptive to anyone.

Secondly, the person being moved might not want to be in a community-based care setting, causing a conflict with an individual's will and preference.

It is difficult to challenge unlawful detainment. Moving people between settings must be done with lawful authority and the ability to challenge and appeal the move. The person being moved should be consulted by the lawful authority so that they can give their opinions, share their will and preference and make their case with whatever level of support they may need.

**Part 8: Authority for research**

**Question 91: Should the AWI Act be amended to allow the creation of more than one ethics committee capable of reviewing research proposals involving adults lacking capacity in Scotland?**

**No.**



The ALLIANCE believes that the existing ethics committee responsible should be sufficiently funded and resourced to conduct any additional work that may arise.

**Question 92: In research studies for which consent is not required for adults with capacity to be included as participants, should adults with incapacity also be permitted to be included as participants without an appropriate person providing consent for them?**

**No.**

Any research conducted should be ethical, seeking consent from participants and those who know them best. Research should never be conducted without someone's consent or where it might conflict with their will and preference.

**Question 93: Should Scotland A REC (or any other ethics committee constituted under Regulations made by the Scottish Ministers in the future) have the ability to determine that consent would not be required for adults with incapacity to be included as research participants, when reviewing studies for which consent would also not be required to include adults with capacity as research participants?**

**No.**

In certain instances, consent may not be required if research does not involve primary research with the individuals themselves, but instead involves investigating or analysing data.

**Question 94: Should the AWI Act be amended to allow researchers to consult with a registered medical practitioner not associated with the study and, where both agree, to authorise the participation of adults with incapacity in research studies in emergency situations where an**



**urgent decision is required and researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative in time?**

**No.**

Please see our answer to question 92.

**Question 95: Should the AWI Act be amended to allow researchers to enrol adults with incapacity in research studies without the consent of an appropriate representative of the adult, in emergency situations where a decision to participate in research must be made as a matter of urgency, where researchers cannot reasonably obtain consent from an appropriate representative of the adult, and where researchers act in accordance with procedures that have been approved by Scotland A REC (or any other ethics committee constituted by regulations made by the Scottish Ministers)?**

**No.**

Please see our answer to question 92.

**Question 96: Should the AWI Act be amended to permit researchers to nominate a professional consultee to provide consent for adults with incapacity to participate in research, in instances where researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative?**

**No.**

Please see our answer to question 92.

**Question 97: In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the AWI Act be amended to allow adults lacking**



**capacity to participate in research that investigates conditions that may arise as a consequence of their incapacity?**

**Yes.**

We believe that research investigating incapacity is necessary to understand the impact and outcomes of people subject to the Adults with Incapacity Act. It is vital that people participating in research must be involved as much as possible as equal partners in research. There must be the appropriate safeguards put in place whereby consent is sought by the participant and their family, unpaid carer and/or trusted person.

**Question 98: In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the AWI Act be amended to allow adults lacking capacity to partake in research that investigates conditions they experience that do not relate to their incapacity?**

**Yes.**

Please see our answer to question 97.

**Question 99: Should the AWI Act be amended to allow adults with incapacity the opportunity to participate in any research; regardless of whether the research explores conditions that relate to their incapacity or investigates conditions that they experience themselves?**

**Yes.**

We know that a wide variety of research cohorts is vital to building up a good research and evidence base. However, research disproportionately targets vulnerable people. To mitigate any negative consequences, researchers must follow the will and preference of individuals, their families, unpaid carers and trusted persons, and involve them in the research process as much as possible. Any participation must only occur if consent





has been actively and knowingly given by the individual and those who know them best.

## About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,600 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

## We aim to:



- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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W: <http://www.alliance-scotland.org.uk/>

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