mental welfare
commission for scotland

Care and treatment for people with alcohol related brain damage in Scotland

A report on visits to people and services across Scotland in 2021

September 2021

Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

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Foreword – Julie Paterson, chief executive

"Discriminatory perceptions of a 'self-inflicted illness' can lead to people with a diagnosis of ARBD being extremely vulnerable, marginalised and socially isolated."

The Mental Welfare Commission has a statutory safeguarding role for people whose mental capacity to make decisions, or to take actions to promote or safeguard their welfare, is impaired. Alcohol-related brain damage (ARBD) is one such diagnosis that may lead to such impairment.

The pathway to a diagnosis of ARBD, and to getting specialist support to meet individual needs and outcomes, can be challenging and complex – both for the person affected and for those people important and close to them.

Discriminatory perceptions of a 'self-inflicted illness' can also lead to people with a diagnosis of ARBD being extremely vulnerable, marginalised and socially isolated.

For some people where there are concerns about their safety and judgement, guardianship orders - which allow a family member or a local authority to take decisions on the person's behalf - may be applied for under adults with incapacity legislation to address risks and to ensure appropriate treatment, care and support.

While guardianship orders can be very useful in helping manage issues for someone with alcohol related brain damage, we have long-standing concerns about the availability of specialist support for those people.

To help address those concerns, in 2019 we published a good practice guide on this subject, for use by health and social care services across Scotland.

This report is the next stage. It looks specifically at 50 cases where people have been given a diagnosis of ARBD and are also subject to a welfare guardianship order.

Our intentions here are to understand whether our ARBD good practice guidance is being followed by health and social care services, and to learn more about the care arrangements in place, and the application of the critically important principles of adults with incapacity law.

This report details some of the specific actions we took following our contacts with those 50 individuals (and their family/carers where appropriate) across 27 of Scotland's 31 Health and Social Care Partnerships (HSCPs).

We also report on our findings, a summary of which is noted below. There were many positive examples of good care, which we highlight in this report, but also areas of concern.

We found many of the people we met were living in care homes where they were much younger than the other residents. Those commissioning services must consider whether they are breaching the person’s human rights if the person finds themselves compelled to live in a setting which they would never choose.

We make recommendations about areas of care and treatment we believe could and should work better, and we will follow those up.

I hope our report will be widely shared and discussed, and others will join us in seeking improvements for this vulnerable group.

Summary findings and recommendations

Recommendation 1: Health and Social Care Partnerships should commission suitable, age appropriate and where possible specialist ARBD services.

As described in our good practice ARBD guidance and further evidenced in this programme of visits to people subject to guardianship orders, inappropriate community care home placements can precipitate dependency and isolation for individuals with ARBD. Despite the advent of self-directed support and our guidance we saw limited development of specialist, innovative approaches and services in Scotland to meet the needs of people with a diagnosis of ARBD. Where we did find this, more positive outcomes were clearly evidenced.

Those commissioning services must consider whether they are breaching the person's human rights if the person is compelled to live in a setting which they would never choose.

Recommendation 2: Health and Social Care Partnerships should ensure allocation of the delegated officer role to a named individual to ensure consistency and continuity.

The Chief Social Work Officer delegates the role of guardian to a delegated officer; the Chief Social Work Officer remains accountable however. We found that the critical role of delegated officer was not always held by a named officer who maintained regular contact with the person subject to the restrictions of the guardianship order. We do not consider this to be in line with the spirit of the legislation. Where a decision has been taken by the local authority to intervene in a person's life on a statutory basis, there should be a named delegated officer building a trusting relationship and ensuring that the order is meeting the person's outcomes in line with the principles of the Adults with Incapacity (Scotland) Act 2000 ('the AWI Act').

Recommendation 3: Community care review activity within Health and Social Care Partnerships should be dynamic, coordinated processes which include review of personal outcomes, care plans, placement, the guardianship order and whether all or some of the powers remain relevant.

Multidisciplinary reviews should be dynamic, coordinated processes informed by the principles of the AWI Act, maximising both the contribution of the person and their carers/relatives where appropriate. We found that reviews did not always focus on outcomes, the placement and the powers of the order. It is important to ensure that those involved are not passive recipients of information but have ongoing relationships that allow them to actively contribute to the review process.

Recommendation 4: Health and Social Care Partnerships' strategic advocacy plans should include focus on accessibility of advocacy support at all stages of the care and support continuum.

We have highlighted the challenges of supporting the rights of people with a diagnosis of ARBD to live as they choose balanced with their rights to access support to maximise their quality of life. The offer of advocacy support is an important safeguard to ensure respect for the rights, will and preferences of the person and not what is considered by others to be in that person’s best interests. Advocacy support is important prior to the guardianship application stage, post guardianship and throughout the provision of continuing care.

- Where recommendations are made to health and social care partnerships, this refers to the joint operational arrangements that exist in a council area between local authority social work services and health care services of the local health board.

Introduction

There are many different terms used for cognitive impairment as a result of alcohol misuse. An expert group, which included representation from the Mental Welfare Commission for Scotland ('the Commission'), produced the report *A Fuller Life* in 2004 [1] and used the collective term, alcohol-related brain damage (ARBD), and this is the term we use here. The definition is as follows:

> *Alcohol related brain damage (ARBD) refers to the effects of changes to the structure and function of the brain resulting from long term consumption of alcohol. There is no single cause of ARBD, which usually results from a combination of factors. These include the toxic effects of alcohol on brain cells, vitamin and nutritional deficiencies, head injury and disturbances to the blood supply to the brain.* (p.2) [1]

People with ARBD can require help to manage their alcohol use and to undertake skills of daily living. The Commission's published report in 2006, *Mr H*, highlighted the vulnerabilities and negative consequences for a man whose ARBD went unrecognised, despite many contacts with health and social work services. At that time, we also heard about a concerning lack of resources available to support people once a diagnosis of ARBD had been made [2].

The Commission undertook themed visits involving people with a diagnosis of ARBD in 2010 [3] and in 2019 we published a good practice guide aimed at those working in partnership with people with a diagnosis of ARBD [4]. The guidance recognises the challenges of supporting the rights of this vulnerable group of people to live as they choose balanced with their rights to access support to maximise their quality of life.

People with a diagnosis of ARBD form a small but very significant vulnerable group in society. There may have been years of problem drinking for each individual, resulting in social, financial, occupational, physical, and forensic consequences. Family, friends or neighbours may have exhausted all efforts to provide support where the person lacks insight into their behaviours and impact. There may also be a stigmatised public perception that the difficulties are self- inflicted. As a result, they require outside agencies to provide support and to meet outcomes that are important to them.

It is against this backdrop that, this year, we chose to visit a number of people with a diagnosis of ARBD who are also subject to a welfare guardianship order. The intention of this themed programme of visits is to build on the Commission's ARBD good practice guidance and its key learning points and to look specifically at the way that guardianship and its principles are used in this context.

What we did

If an adult is unable to make key decisions or take necessary actions to safeguard their own welfare, a court can appoint a welfare guardian to do that for them. The welfare guardian can be a relative, friend or carer. The court can also appoint the chief social work officer of a local authority to be a person's welfare guardian. The law that sets out the roles and responsibilities of guardians is the Adults with Incapacity Act (Scotland) 2000.

Every year we look at how many people are subject to a welfare guardianship order on 31 March. We call this extant guardianships and this tells us the prevalence of welfare guardianships in Scotland. In 2020, there were 553 individuals with ARBD who were subject to a guardianship order. We used this information to help choose the people we wished to visit, selecting by local authority, gender, and order length to identify a sample of 50 individuals that broadly reflected the overall population of people with ARBD subject to a guardianship order.

We then made contact with those 50 people, across 27 local authorities/Health and Social Care Partnerships (HSCPs) in Scotland. Thirty per cent of the people we made contact with were female, 67% were male, and one preferred not to say. Fifty two per cent were under the age of 65 years and 48% were 65–75 years.

Given Covid-19 and the restrictions at the time, 54% of the contacts were undertaken virtually using technology and 46% of contacts were made face to face in the person's home. All 50 people had a confirmed diagnosis of ARBD with 30% of those people also having additional diagnoses, for example mental illness, epilepsy, learning disability. Twenty-nine people were able and willing to give us their views and respond to questions posed.

We are committed to meeting our requirements for equalities monitoring and ask people we meet about protected characteristics. Table 1 presents a breakdown of protected characteristics of the people we met with.

Table 1. Equalities Monitoring

Characteristic	Grouping	n (%)
Ethnicity	White Scottish	44 (91)
	White Other British or White Other	5 (7)
	Not provided	1 (2)
Transgender	Nothing recorded	30 (54)
	No	18 (40)
	Prefer not to say	2 (6)
Sexuality	Nothing recorded	20 (33)
	Heterosexual	19 (41)
	Prefer not to say	*
	Gay	*

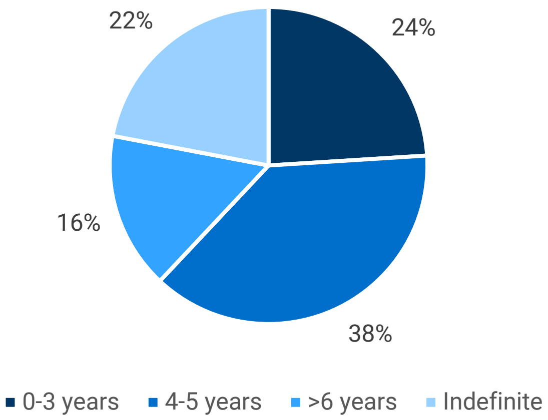
**n<5 or secondary suppression*

Just over half of the people we made contact with (54%) had a local authority guardianship order in place, 43% had a private guardianship order, and 3% had a combination of the two. We found that guardianship arrangements were not always clear:

> *During the visit it became apparent that the care home were under the impression that the relative was the welfare guardian despite it being the Chief Social Work Officer (CSWO). Consequently they have been consulting the relative in all aspects of the person's care. While we agreed that it was good practice to consult, we discussed and explained the fact that decision making lay with the CSWO.*

Most guardianship orders were for five years or less (Figure 1). Fourteen (23%) of the people we made contact with had renewed orders whilst the other orders were new.

Figure 1. Length of guardianship order



Capacity

What we expected to find

The Commission's good practice guidance explains that "There are particular challenges in carrying out capacity assessments with ARBD so assessments should be carefully planned and carried out by specialists wherever possible" (p.33) [4]. For our sample of 50 people, we have assumed that careful planning and specialist assessments, where possible, were carried out at the outset to inform the diagnosis of ARBD given to support the welfare guardianship order application agreed by the Sheriff in each case.

If a person with ARBD stops drinking alcohol and receives good support, they may be able to make a partial or even full recovery. They may regain much of their memory and thinking skills, and their ability to do things independently. The Commission's best practice guidance states that "there are effective treatments for ARBD and legal interventions can often help to ensure these treatments can be delivered, and the chances of long term recovery maximised…." (p.33) [4]. Alcohol related brain damage does not, therefore, always get worse over time.

Anyone who is intervening in the person's life should be aware of the provisions of the Adults with Incapacity (Scotland) Act 2000 ('the AWI Act') and of people's right to liberty under the Human Rights Act 1998. Any restrictions should be legal, proportionate and regularly reviewed. We therefore would expect to see consideration of decision specific capacity assessments as integral to the dynamic care planning process, undertaken based on the individual needs and improvements, or otherwise, evidenced by the person subject to a welfare guardianship order.

The AWI Act ensures that people have access to advocacy and we would expect this service to continue to be offered post guardianship order, recognising the important role of advocacy in terms of long term support, care planning, review and supporting the person to claim their rights. This would include appropriate multidisciplinary reflection on whether the grounds of recall might be met (section 73(3) of the AWI Act).

What we found

Whilst we had assumed that challenges relating to assessments and capacity had been appropriately addressed to inform the original welfare guardianship applications, we found this not to be the case in all of our sample. This renders the order unsafe in our view and we will take appropriate action.

Less than half (42%) of the people we made contact with had received an updated formal capacity assessment since their original guardianship order was granted. Of these, 21 people whose capacity had been re-assessed, the majority (15 people) had received an assessment by a psychiatrist, while five had been assessed by their GP and one by their GP and nursing team.

Reassessments tended to be linked to the timing of renewal of orders, however we also saw active intervention by private welfare guardians at other times, seeking reassessments in light of obvious improvements made by their relatives following receipt of care and support.

The challenges of such capacity assessments were evidenced in one particular case where a reassessment was undertaken by a psychiatrist at the point of renewal of the order. The person was found to have regained capacity to make welfare decisions and the order was allowed to lapse. Three months later other medical staff questioned the person's capacity and the outcome was a further welfare guardianship application. The new order was subsequently granted for a 12 month period (eight months after the original order was allowed to lapse).

For the remaining 29 people who had not had their capacity to make decisions formally reassessed, we noted one person where this should have happened. A psychiatrist had recommended a formal capacity review within 12 months of the guardianship order being granted for this person and this had not happened eight years on. For three people we were told that a reassessment was not required. Examples where reassessment of capacity was not deemed to be required included where additional medical conditions evidenced further decline and/or life limiting illness.

Of the remaining 25 people who had not had their capacity assessed since their guardianship order was granted, we could only find two cases where there was a plan to formally reassess capacity. Where capacity had not been formally reassessed we found that there was generally consideration given to the issue of capacity at review meetings. Improvements in the person's ability, circumstances and skills were often referred to; however, capacity was not thought to have recovered.

As our guidance states, where it is established that capacity is recovered, professionals and relatives may ultimately have to accept that people have the right to make choices, even if this means resuming a previous chaotic lifestyle. Recall of the order, prior to its expiry date, would be expected in such circumstances where capacity is recovered and the grounds of the order are no longer met. Review of Commission records over the past five years confirms that only two guardianship orders have been recalled where the person had a diagnosis of ARBD.

Indeed we found that there have only been a total of 16 orders recalled across Edinburgh City, Aberdeen City, East Ayrshire, Aberdeenshire, South Lanarkshire, Glasgow, East Lothian and Fife. Twenty six other HSCPs have recalled no orders in the past five years. This may be entirely appropriate based on individual needs but it may also represent a lack of dynamic care planning and review of powers and orders required.

Current living situation

What we expected to find

The intention of the Social Care (Self-directed Support)(Scotland) Act 2013 is to offer choice, control and flexibility to enable people to receive the kind of support they want, where they want it and when they want it. Each person is a unique individual and people with ARBD who are subject to guardianship orders are no exception. By drafting individually framed powers, guardianship orders can facilitate personal outcomes focussed care.

Personal outcomes focussed care is reportedly more challenging for services than providing standardised 24 hour care in a care home setting, however many people with a diagnosis of ARBD are under 65 years and may not be suited to care home settings which are mostly registered for older people (median age 84 years) [5], nor do they fit well into units for young physically disabled people, or for younger people with a learning disability.

Following earlier reports and good practice guidance, we expected to see further development of specialist, innovative approaches and services in Scotland to meet the needs of people with a diagnosis of ARBD; like anyone else, people with an ARBD diagnosis are entitled to care provision which reflects their age and individual interests.

What we found

Seventy percent of our total sample were living in care home settings, 12% were living in the family home and 18% were living in other settings e.g. hostel or supported accommodation. Fifty-two percent of our sample, 26 people, were aged under 65 years, the youngest in their 30s. Seventeen of the 26 people were reported as living in a care home setting. Following review of the Care Inspectorate's website, only one of these care homes was registered as a specialist service in relation to 'brain damage including alcohol related brain damage'.

Many of those with ARBD may find themselves living in a 24 hour care home setting with others who are decades older and who may be frail, have progressive dementia or other degenerative conditions of old age. The person with ARBD may feel out of place. One of the people we met, who was younger than 65 years, was living in a care home registered for older people and had retained skills of daily living. In his care plan it was noted they were "independent with all personal care tasks" and "required minimal assistance". Information provided suggested that they were "not a mixer and preferred to sit in their room most of the time". Although we were told that this person "had never been a mixer", this setting did not really provide much in the way of opportunity to choose to do so. One carer told us their relative was:

> *…too young to be in a care home so we worked with social work and others to get them back to the community. They are much happier now in their own home.*

Those commissioning services must consider whether they are breaching the person's human rights if the person finds themselves compelled to live in a setting which they would never choose.

We had hoped to see the development of more bespoke, innovative approaches to care and support based on the specialist needs of people with ARBD. Our findings were unfortunately similar to our last themed visiting programme to people with ARBD in 2010, namely that some services had developed in response to demand, becoming specialists by expertise rather than designation [3].

We reviewed the websites of care homes to understand the detail of registration and specialisms advertised. In some cases we were surprised by the apparent range of age, needs and potential desired outcomes in one registered care setting.

Care and support

What we expected to find

As discussed above, the majority of the people we met during this visit were either living in a registered service or receiving support from a registered service. We would therefore expect to see care plans in place which address the care, treatment and interventions that a person should receive to ensure that they get the right care at the right time for them. These care plans should focus on individual needs and the person's desired outcomes, recognising the potential for rehabilitation in each case as well as the rights, will and preference of the person.

Our good practice guidance on ARBD highlights five stages of treatment for people with this diagnosis and for most of the people we visited they were in the final stage of this continuum – long term maintenance and relapse prevention. In this phase, building positive social relationships and developing structure and routine are important to improve outcomes and we expected the care plans to reflect this.

Our good practice guidance notes that successfully preventing alcohol consumption may not only avoid further harm for the person, but may also create potential for the improvement of functioning, and the maximising of opportunities to gain social capital and develop new interests and relationships [4]. Consequently we would expect to see care plans which detail how access to and consumption of alcohol is managed and for any care plans which include restrictions in these areas to be appropriately authorised by a specific power contained within the welfare guardianship order.

As stated previously, ARBD presents complex ethical issues around human rights and respecting autonomy while keeping people safe. Our guidance therefore highlights the importance of multi-disciplinary planning to ensure holistic, personal outcomes are promoted. During this visiting programme we expected to see multi-disciplinary involvement, including advocacy, where appropriate, to ensure the availability of informed advice, guidance and specialist support and to contribute to complex ethical decisions which may be required.

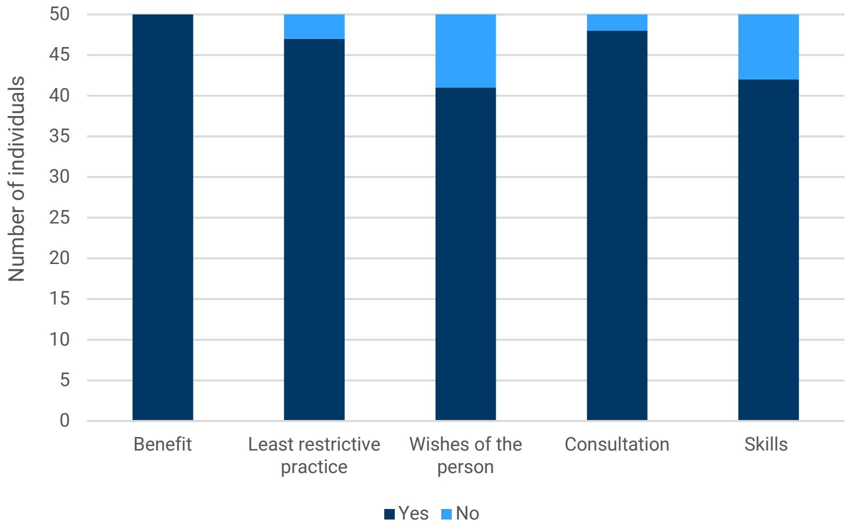
Meaningful activity is an important element of contributing to a good life and for some whose lives have been dominated by using alcohol, opportunities to participate in positive, rewarding activity may have been reduced over long periods of their lives. Finding alternatives to this lifestyle can be a challenge and it is important for anyone who is supporting an adult with ARBD that they understand this and support them to find activities which can enrich their quality of life wherever possible.

We made contact with a number of people who were living in environments which were registered for older people – in some instances we saw people living in care homes where they were 30 years younger than other residents. We expected to find bespoke activities in these instances which recognised the age and preferences of the individual, took account of the person's past and present wishes and also encouraged use of skills (as required by the principles of the AWI Act).

What we found

We looked at whether the key principles of the AWI Act (benefit, least restrictive practice, considering the wishes of the person, consultation with significant others, and exercising and developing skills in relation to relevant decisions) were taken into account. We found that the benefit principle was considered for all, however we found that the wishes of the person were not taken into account for nine people, skills for eight people, least restrictive practice for three and consultation for one (Figure 2).

Figure 2. Application of principles



The aim of the AWI Act is to both protect people who lack capacity to make particular decisions and to maximise their involvement in making decisions about their own lives as far as they are able to do so. We would therefore expect to see all principles fulfilled for all people.

The principles of AWI law are important safeguards. We mention earlier about the dilemmas faced where some parties may determine 'benefit' as a person with ARBD living in a care home with support, with no independent access out with the care setting and no opportunity to buy alcohol. The person themselves may hold the opposite view. There may be a conflict of interest or undue pressure. Failure to take the other four principles into account could render the 'safe' placement as a breach of the person's human rights.

To find nine cases where there was no evidence of the person's wishes being taken into account was a significant concern for us and reinforced the need to ensure advocacy support is available to people receiving continuing care arrangements. Advocacy is one of the critically important safeguards to ensure respect for the rights, will and preferences of the person, on an equal basis with others, and not what is considered by others to be in that person's best interests.

There was evidence of care plans in place for all those we made contact with who lived in or received support from a registered care setting (46 people).The degree to which the care plans were person centred varied. In the main, all the care plans we saw covered basic individual needs relating to physical health and personal care. Others included more specific plans around social, recreational, spiritual and financial needs, all of which have a bearing on the person's recovery.

The extent to which alcohol use was addressed also varied. Of the 45 care plans we saw, 27 did not include how alcohol was managed. For a number of these, we heard that alcohol misuse was no longer relevant for the person as they had been abstinent for some time whilst for others we heard that alcohol use was prohibited, although there was no care plan which detailed how this was managed or legally authorised.

This picture was complicated because for some of the people whose alcohol use was reported as no longer an issue, this was due to their current living environment which limited or prevented access to alcohol e.g. a hospital or a care home setting.

Of the 16 people for whom there was a care plan which restricted/prohibited alcohol use, 11 of these had an appropriate power contained within the welfare guardianship order. For the remaining five people, this restriction was not legally authorised.

A had been in hospital for almost two years and was preparing to move to community supported accommodation. Prior to hospital admission, A had a lengthy alcohol dependence and involvement from a range of specialist alcohol/addiction services. A had been assessed as lacking capacity to make a range of decisions in relation to their welfare and the transition to a community setting was being authorised by a welfare guardianship order with powers to decide where they lived and to return them there in the event that they absconded. There were no powers contained within the order to manage access to and use of alcohol, on the basis that this had not been an issue for the duration of their lengthy hospital stay. This was discussed at length during our visit and highlighted the balance between the least restrictive intervention and ensuring sufficiently robust powers were in place in anticipation of a change in living arrangements where risks were historically evidenced.

For nine of the people we visited, alcohol consumption continued to feature in their day to day lives although for most this was minimal, not deemed to be problematic and was included in a care plan. For a small number, however, this ongoing alcohol use was impacting significantly on their ability to remain safely in their current setting and plans were progressing for a move to a more structured environment with further restrictions on the use of alcohol. For one person, we advised that a review of current welfare guardianship powers should be undertaken to ensure that any additional restrictions would be appropriately authorised.

We visited people who received specialist ARBD services (registered as such with the Care Inspectorate) and the care plans we saw in these instances were more specific to the needs of this group. In one service we saw examples of the use of the Outcome Star care planning model.

This care planning process can cover some or all of the following areas of an adult's life:

- Motivation and taking responsibility
- Self-care and living skills
- Managing money and personal administration
- Social networks and relationships
- Drug and alcohol misuse
- Physical health
- Emotional and mental health
- Meaningful use of time
- Managing tenancy and accommodation
- Offending

For each of these areas there is a detailed ladder to help the person work out where they are in that area of their life and what their next step will be. Effective outcomes focussed care planning such as this, maximising independence and achieving outcomes important to the person is the standard we would hope to see consistently for all people with ARBD.

Activities are an integral part of being alive. Thirty-four of the people we saw reported positively on the evident structured, meaningful activities in which they were routinely engaged. We saw a range of activities tailored to individual preferences including swimming, attending local football games, walking groups, cooking and equine therapy. These were often supplemented by activities within care settings (usually organised by activities coordinators) and involvement with family activities. There was a recognition that for some, activities had been significantly curtailed due to Covid-19 restrictions but there was evidence that these were slowly resuming as restrictions began to lift.

In B's case, activities were organised to achieve the outcome he said he wished to achieve:

B was accommodated in specialist ARBD supported accommodation – after spending a significant time in hospital and the preceding period using alcohol excessively whilst living on the streets, their goal was to secure their own tenancy and to be self-sufficient. They had said that their life was dominated by using alcohol over a number of years and they were unsure how they would find alternative interests which would divert them from resuming their previous lifestyle.

Consequently their care plan and meaningful activities were focussed on these outcomes and included self-care, household management, budgeting and exploring activities which could offer a more meaningful and positive use of time. This was a very practical care plan aimed at realising their personal goal of independent living and as a result they demonstrated a strong commitment and engagement in the process.

Six people told us that they were unhappy with the level and nature of activity they had. These related mainly to younger adults who were accommodated in care homes primarily catering for older people. There was no evidence of bespoke arrangements in place for them.

Our ARBD guidance highlights the importance of considering a care home placement against the principles of the AWI Act and the requirement under the United Nations Convention of the Rights of People with Disabilities to respect the “rights, will and preference” of disabled persons. In considering ongoing compulsion under the AWI Act, it is important to consider whether the placement is breaching the person’s human rights by imposing a way of life which is unacceptable to them. The answer is to develop more appropriate services.

Advice was given in these instances that the current placements and care plans should be reviewed as a matter of urgency. We will follow this up.

For 22 of the people we made contact with, there was evidence of multi-disciplinary involvement, and for three of these people this included support from a specialist community ARBD service.

The composition of this multi-disciplinary support varied depending on the needs and agreed outcomes of the individual but predominantly comprised of psychiatry, community psychiatric nurses, social workers, mental health officers and third sector providers. In addition, we heard that referrals could be made for additional supports and that links were established with other services to aid ease of access when required. During our visit programme we noted the absence of advocacy support and speech and language therapy in some cases and suggested referrals on the person’s behalf which were agreed.

Our good practice guidance highlights the importance of a multidisciplinary approach at various stages of the ARBD pathway. For the majority of the people we visited, their circumstances were indicative of longer term care and relapse prevention and so our findings in relation to the prevalence of the multidisciplinary approach would seem, in the main, to be appropriate.

We heard in some instances that there had previously been involvement from a multidisciplinary team but that the need for this involvement on an ongoing basis was no longer evident. We accept that this is, in some instances, appropriate but would advocate for re-referral if support staff, family/carers witness any material change in the person’s presentation which could be indicative of an impact on their capacity so that this can be reassessed.

Abstinence from alcohol, a healthy diet and compliance with prescribed medication can all contribute to an improvement in a person’s cognition and functional abilities, as well as their capacity to make informed decisions about their welfare. In these instances, multidisciplinary input can ensure that these changes are recognised and accounted for both in terms of a reviewed care plan and the consideration of the need for ongoing guardianship powers.

Where we saw the involvement of an ARBD service, either community based outreach teams or indeed specialist ARBD providers, there was more evidence of positive outcomes for the person on the basis of enhanced knowledge of the presenting symptoms and a more tailored response to these.

Guardianship supervision

What we expected to find

We expected to find welfare guardianship orders which were supervised in line with AWI codes of practice.

In relation to private guardians, Section 10(1) of the AWI Act states that a local authority must: “supervise a guardian appointed with functions relating to the personal welfare of an adult in the exercise of those functions”.

We expected that the private guardians we met would have an allocated supervising officer from the local authority in which the person subject to the order lived. The supervising officer holds a very important role to support, advise and guide the welfare guardian to fulfil their responsibilities according to the principles of the AWI Act. It is expected that the supervisor would visit the guardian and the person subject to the guardianship order (at an agreed timescale) to monitor the use of and recording of powers and to ensure that the powers are making a positive difference to the person’s welfare.

Where the CSWO of the local authority has been appointed as guardian, the duties can be delegated. Section 64(9) of the AWI Act allows the CSWO seven working days, after appointment by the sheriff, to notify the person and the Commission (where incapacity is related to mental disorder) of the name of the person nominated to act on behalf of the CSWO as guardian.

The person nominated to act on behalf of the CSWO is known as the delegated officer and should receive support and supervision to assist them to fulfil this key role. We expected that, for all people we met with a local authority guardianship order in place, a named delegated officer would be in place. The delegated officer’s role includes:

- Ensuring they can be contacted by relevant parties
- Ensuring the delivery of the care plan
- Holding regular review meetings
- Monitoring the adult’s personal welfare
- Proactive exercise of the powers to promote personal welfare.

We expected to see robust, dynamic review processes which considered the existing care plan, whether it remained appropriate and was meeting the person’s outcomes, whether the powers contained within the order continued to be relevant and were being used in line with the principles of the AWI Act. In addition, we expected to find that where care and support was being provided by someone other than the guardian that relevant powers had been duly delegated to the care provider and that there was a record of this delegation. This ensures clarity for providers on the scope and limitations of their use of formal powers to deliver a care plan, particularly where this includes a degree of restrictive practice.

What we found

The 20 private guardianship orders within our sample all had an allocated supervising officer, albeit two were allocated after contact from the Commission as part of this visiting programme. It was noted that although face to face visits had been curtailed during Covid-19 restrictions and that some contacts had been made by telephone, 14 people had been visited in the last 12 months. The remaining six had not been visited for a number of reasons ranging from a proactive decision that ongoing supervision was not required as per The Adults with Incapacity (Supervision of Welfare Guardians etc. by Local Authorities) (Scotland) Amendment Regulations 2014, to no perceived need, Covid-19 restrictions and workload pressures for the supervising officer. One guardianship order appointed a joint private guardian and the CSWO. While a Delegated Officer had been appointed to work alongside the private guardian, there was no Supervising Officer in place. Advice was given to seek the allocation of a Supervising Officer as we felt that there could be a potential conflict of interests for this role to be fulfilled simultaneously by the Delegated Officer.

The Adults with Incapacity (Supervision of Welfare Guardians etc. by Local Authorities) (Scotland) Amendment Regulations 2014[6] revised the requirements for the supervision of private guardians. These amendments enabled discussion between guardians and the local authority about the need or not for supervision and the regularity with which this supervision was conducted. In a number of cases, we heard that there are local policies in place which dispense with the need to allocate a Supervising Officer to support a private guardian. We felt that this blanket approach did not take individual circumstances into account and we suggested that the 2014 regulations should be applied to reflect the need for ongoing supervision and to agree an appropriate timeframe for formal supervision to occur.

Where supervision of the welfare guardian has ceased or been varied, practitioners are reminded that they should notify the Commission of the revised arrangements.

Where there was a lack of review, there was reliance on the private guardian or the care provider to raise any welfare concerns with the supervising officer. For an adult with a diagnosis of ARBD, living in a supported placement relieves carers and relatives of some of the issues and stresses they may have had to deal with when the adult was living independently. The placement, however, while offering this protection may not provide a quality of life that is acceptable to the person themselves and the need for an objective assessment of the suitability of the placement and the use of formal powers to authorise it should be seen as a role for the supervising officer. A further protective factor is the involvement of advocacy support; we found little evidence of active advocacy support in the cases we reviewed.

We made contact with 29 people who were subject to local authority orders, all but three of whom had a named delegated officer. We heard that in one area, a delegated officer is not routinely appointed but that in the event that social work intervention is required, a referral to duty social work is the pathway for this. We do not consider this to be in line with the spirit of the legislation. Where a decision has been taken by the local authority to intervene in a person's life on a statutory basis, there should be a lead professional overseeing this intervention to ensure continuity and to ensure that the order is meeting the person's outcomes in line with the principles of the AWI Act.

Similarly, we heard that for some CSWO orders the delegated officer role lies with a review team, not with a named professional. This review team formally review a placement on an annual basis. As we have discussed throughout this report, ARBD is a complex condition which impacts significantly on an adult's cognitive abilities, comprehension, capacity and communication. These complexities may be difficult to take into account where the reviewer is unfamiliar with the person's presentation and conversely where the person does not know the reviewer. It is difficult to understand how a 'one off' annual review meeting can fully assess the effectiveness of an order and the need for the powers on an ongoing basis. The delegated officer role should be an active participant in the assessment process rather than a passive recipient of information received from others.

C is 60 years old and became subject to a CSWO Welfare Guardianship in 2010. The order was granted on an indefinite basis. C is accommodated within a care home. The care home does not have a copy of the guardianship order and there is no evidence that there has been any discussion in relation to the delegation of powers to the care home. C does not have a named delegated officer from the local authority. During the visit we saw care plans which were basic, lacked detail despite the complexities of C's needs and were overdue for review. There was no reference to the powers within the guardianship order within any of the care plans, despite this being a locked door facility and C being unable to leave the premises without support and supervision. C is supported to access money by staff from the care home but this has proved difficult over covid-19 lockdown as they have been unable to get to the bank. C has substantial savings which they have been unable to access or use creatively over this period. We made recommendations to the local authority to address these observations urgently.

Where we saw the best outcomes for the person with ARBD was when the delegated officer knew the person well, was in regular contact with them and the care provider and was fully familiar with the powers in place and their use. Best practice also included care plans which evidenced full discussion between the delegated officer and the provider detailing the responsibilities and authority of the provider regarding the day to day powers.

In July 2020, the Commission updated the good practice guide *Working with the Adults with Incapacity Act*, aimed at people working in adult care settings. Our expectation is that a record of delegated powers should be retained within records. Within this guidance above, practitioners can find (p.14) a guardianship and power of attorney checklist which will assist in conducting and recording the discussions between the guardian and the provider to ensure clarity of roles and responsibilities [7].

Medical care and treatment

What we expected to find

Part 5 of the AWI Act gives a general authority to treat a person who does not have the capacity to consent to that treatment. Under section 47(4) of the AWI Act, "medical treatment" includes any procedure or treatment designed to safeguard or promote physical or mental health.

The appropriate healthcare practitioner is required to issue a certificate of incapacity for the treatment in question (section 47(1)) and, in doing so, must take full account of the principles of the AWI Act. If the health care practitioner issuing the certificate is aware that a welfare proxy exists, the practitioner, where it is 'reasonable and practicable to do so', should obtain the consent of that proxy section 50(2).

For adults requiring multiple or complex healthcare interventions, we would expect to see a detailed treatment plan attached to the certificate of incapacity and held in the person's case record. We would also expect to see recording of who had been consulted as part of the process.

We are often asked if a 'section 47 certificate' is required if there is a proxy decision maker with the power to consent or withhold consent to medical treatment. Our guidance is clear that a section 47 certificate of incapacity is still required, as well as the consent of the proxy decision maker.

If the person does not have capacity to be consulted in relation to a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) certificate, we would expect that any DNACPR certificates in place evidenced due consultation with proxy decision makers and took account of the principles of the AWI Act, specifically benefit to the individual, past and present wishes of the individual and consultation with relevant others. The decision regarding DNACPR is however a clinical one.

What we found

With the exception of four people, there were medical powers included in the guardianship order. Where we were told that a section 47 certificate was required to authorise routine care and treatment (38 people), we could see that certificates were in place for 32 people. We followed up on the remaining six. Two people were subsequently deemed to have capacity to consent to routine care and treatment and in the case of four others, advice was given to discuss the need for section 47 certificates with the relevant medical practitioner. It is important to state that if a section 47 certificate is not in place when it should be, the treatment given is unlawful.

Where we saw section 47 certificates (in 32 instances), 24 of these had accompanying treatment plans. For the other eight, we were unable to ascertain if this was because the treatment provided was not regarded as sufficiently complex to warrant a treatment plan or if there was a conscious decision taken that this was not required.

Where section 47 certificates were in place, only half of these evidenced consultation with the welfare guardian. This is a concern. Section 50(2) of the AWI Act determines that a section

47 certificate does not confer authority to treat if there is a known welfare proxy who can be contacted and who does not agree with the proposed treatment. Healthcare practitioners are reminded that this process of consultation with proxy decision makers is a vital component of the authority to treat (the exception being where there is evidence that it would not be reasonable or practicable to do so).

In terms of DNACPR certificates, these were evident in the casefiles of 13 of the people we visited with consultation with proxy decision makers recorded in 12 of these. We asked the provider to review this certificate with the medical practitioner to consider if this decision remained appropriate and to ensure that any decision relating to the DNACPR certificate is informed by consultation with relevant parties.

Financial situation

What we expected to find

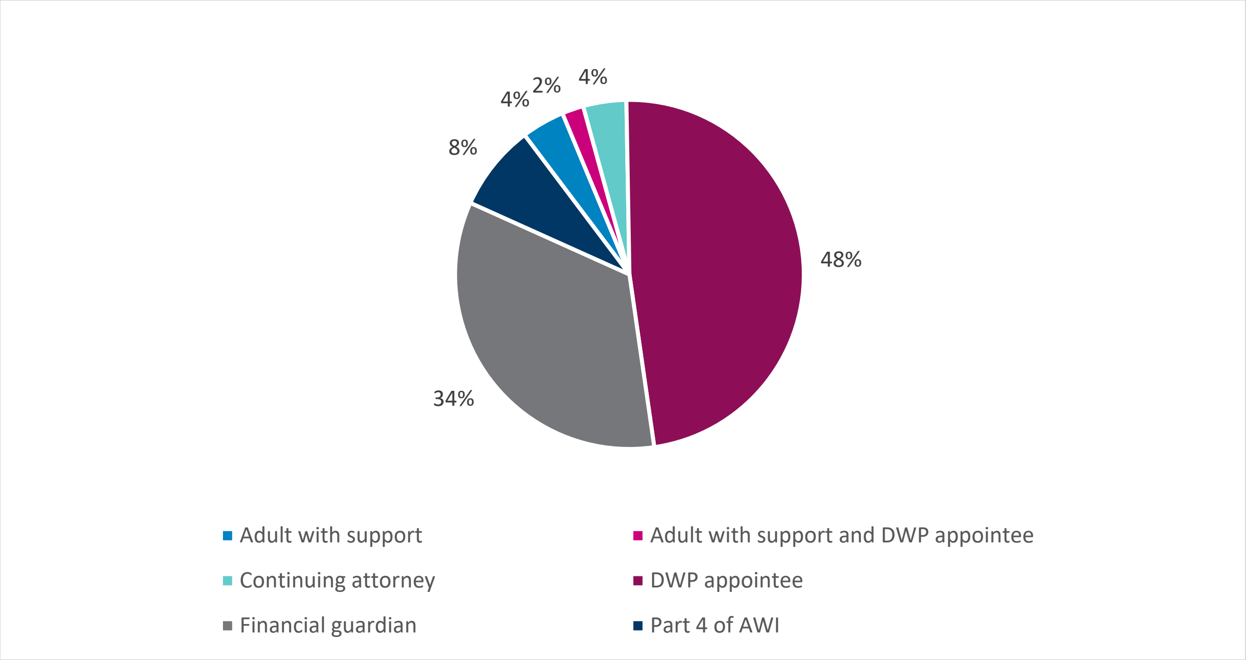
Every person should make their own decisions with regard to financial and property matters, as far as possible, but if someone lacks capacity to make certain decisions and these need to be made by others, this must be done in line with the law and its principles. Our good practice guidance *Money Matters* provides a useful overview for a range of practitioners tasked with safeguarding the welfare and finances of adults who lack capacity [8].

There are legal and ethical issues about how to balance the rights of individuals with the need for intervention where the person may be at risk, including risk of exploitation. For example, those with financial powers may take action to prevent a person with ARBD from having sufficient money to drink alcohol. In such circumstances, we would expect to see evidence of the role of independent advocacy to ensure that people feel empowered to play an integral part in the critical decision making process and to ensure adherence to legislative principles.

What we found

We looked at how the person's finances were managed. About half were managed by a Department for Work and Pension (DWP) appointee and about a third by a financial guardian. In fewer cases the adult themselves, with or without support, a continuing attorney or Part 4 of the AWI Act were the main support systems for the person's finances (Figure 3).

Figure 3. Responsibility of the adult's finances



Although our inquiries suggested that financial arrangements were in place and individuals had appropriate funds available to them, this view was not always shared by the person themselves.

D was frustrated by the DWP appointeeship in place. They told us that they shopped for their own food, clothes and bought a pet but did so with staff support. D told us that they had no intention to buy alcohol and wanted the freedom to have direct access to their own monies. The specialist ARBD team were fully aware of D's wishes, the principles of the Act and the importance of an updated capacity assessment involving occupational therapy and psychology to inform a decision regarding recall or otherwise of the order.

It was good to see evidence of D at the centre of decision making; whilst they had been offered advocacy support and previously had this, D no longer felt this necessary as they were confident in their ability to express their own views and be listened to.

Family/Carers

What we expected to find

The impact of ARBD on families/carers often results in strained and fractured relationships, with many people becoming estranged from their families. This impact should not be underestimated.

People with ARBD who are still using alcohol may present antisocial behaviour and may be at risk of stigmatisation, exclusion and of being marginalised. This can be difficult for family/carers when seeking support, particularly if they come across the view that the individual is choosing to drink alcohol and therefore making a 'lifestyle choice'. Many relatives/carers often feel that they have nowhere to go for help.

As part of this themed visit we wanted to find out more about family/carers' experience. We spoke with 16 carers who were related to the individuals diagnosed with ARBD. Eleven of those we spoke to had been appointed as the person's welfare guardian.

We wanted to find out more about the circumstances prior to diagnosis and the making of the guardianship order along with the important views of the family/carers post diagnosis and support.

What we found

The majority of those we spoke with told us that they had tried to seek help earlier on in their relative's journey but did not get the help/support that they felt their relative needed at that specific time. They told us that the situation would often end up in a crisis, many times resulting in hospital admissions. Many family members or carers told us that they were shocked by their relative's squalid living conditions, their poor physical health and poor mental health prior to the guardianship order being granted. Below is what we heard from family/carers.

> *GP was dismissive stating that their drinking was a life choice and relative/carer did not feel that his concerns were listened to or taken seriously.*
>
> *Family relationships were strained, the family had tried to get support from the GP however had been advised that it was their relative's choice to consume alcohol.*
>
> *It put a huge strain on family relationships due to the impact alcohol had on her life.*
>
> *It impacted on his whole life with broken relationships with partners and family.*
>
> *No support for her or her father until diagnosis in 2017.*
>
> *Seen as a 'problem drinker'.*
>
> *Spent five, six years trying to get help.*

While many of the family/carers who took part in our themed visit reported positively about the care and support that their relative was now receiving, some told us that caring for someone who has ARBD had had devastating and long-lasting effects on the whole family. In terms of relationships, some carers shared with us that roles had been reversed whereby they were no longer in the role as son/daughter but in fact now parenting their 'parent'. Whilst others told us of the difficulty of being estranged for many years and now being back in their life, their relative sadly now did not always recognise them due to the cognitive impairment.

Eleven of the relatives/carers we spoke with were also the appointed welfare guardians, sometimes making very difficult decisions on behalf of their relatives, at times impacting on their relationships. Hearing these stories evidenced why it is so important that the welfare guardian receives the support they are entitled to in order to fulfil their critical role as guardians but also as son, daughter, sister, brother or whatever important role they fulfil.

We are clear that family/carer involvement should be supported at every level and at every stage as appropriate. Where we found that this had happened we heard about good progress being made and relationships developing and flourishing, for the person and for the family members important to them. Below is some feedback we received from some of the people we spoke with.

> *He has never been better looked after and he now has a quality of life he has never had as his sole priority used to be drinking*
>
> *He is maintaining his independence and there is a difference in him since he left the care home.*
>
> *Staff provide the necessary care, support and guidance to ensure he is content and his needs are met.*
>
> *Since the order was granted and he has stopped drinking alcohol I have seen a huge improvement in his ability to look after himself.*

We asked family/carers about any difficulties where their relative was still consuming alcohol. We know that balancing rights, principles of the AWI Act and knowing when to intervene can be difficult for welfare guardians, carers and multidisciplinary staff teams. Most of the relatives/carers told us that their relatives were no longer drinking and they were relieved about that.

Whilst family/carers were relieved that their relatives were generally receiving better care and support now they confirmed our findings that some resources did not provide enough stimulation or fully address the needs of individuals who are younger and more active.

One guardian told us of their "frustration at the lack of resources for people with ARBD". We share this view.

Our intervention

We provided a range of advice and guidance as part of the visiting programme we undertook.

We discussed the contents of our ARBD guidance and shared this with care home staff. We explained the role of the welfare guardian, how this differed to the role of the next of kin and how important engagement and participation is. We explained what is meant by delegating welfare powers to the care home and how this should be recorded. We explained the purpose of section 47 certificates to authorise treatment even where a welfare power existed in relation to treatment.

Whilst reviewing care plans we found that a number of them contained restrictive practices which were not authorised by the powers within the guardianship order and we asked for this to be reviewed with the private guardians or delegated officers as a matter of urgency.

We advised registered providers to seek a copy of the guardianship order for their records so that they were fully aware of the scope and limitations of the powers and we urged providers to discuss which of the powers contained within an order were being delegated to them on a day to day basis. We have created a document to record this discussion which we hope will be helpful. [9].

We requested that action be taken in relation to section 47 treatment specific certificates where we found that they should have been in place but were not. Where there were gaps in the supervision of guardians we highlighted this and where we thought reviews of capacity or of the placement were necessary we asked that this be progressed. We also asked that an investigation be progressed in relation to finance irregularities. On a number of occasions we asked that consideration be given to referral to advocacy services, noting that advocacy involvement had been in place historically, perhaps in relation to the mental health act, but not now, despite this being necessary for some people we met, in our opinion. We asked that the lack of meaningful activity be addressed for all those who reported to us that this was not acceptable. Where we believed an order not to be safe, we took action to address this.

We will be following up on each individual action discussed as part of this visit programme to ensure that all agreed actions have been completed for the person.

We will also be requesting information from local authorities and health boards about how they have been fulfilling their duties to collaborate to secure availability of independent advocacy services in their area as per the duty imposed under the Mental Health (Care and Treatment)(Scotland) Act 2003. We will continue to report to the Scottish Mental Health Review our view that legislation in relation to incapacity should not simply encourage advocacy use but ensure the person has an express right to this critical support.

We are also keen to better understand the landscape of specialist ARBD services and teams across Scotland and we will work with Health and Social Care Partnerships to map this information and detail. We will also discuss the criteria for care home registration with the Care Inspectorate to both understand this and to support transparency and clarity regarding expectations of service provision. We will complete all actions within six months.

Summary and recommendations

Recommendation 1: Health and Social Care Partnerships should commission suitable, age appropriate and where possible specialist ARBD services.

As described in our good practice ARBD guidance and further evidenced in this programme of visits to people subject to guardianship orders, inappropriate community care home placements can precipitate dependency and isolation for individuals with ARBD. Despite the advent of self-directed support and our guidance we saw limited development of specialist, innovative approaches and services in Scotland to meet the needs of people with a diagnosis of ARBD. Where we did find this, more positive outcomes were clearly evidenced.

Those commissioning services must consider whether they are breaching the person's human rights if the person is compelled to live in a setting which they would never choose.

Recommendation 2: Health and Social Care Partnerships should ensure allocation of the delegated officer role to a named individual to ensure consistency and continuity.

The Chief Social Work Officer delegates the role of guardian to a delegated officer; the Chief Social Work Officer remains accountable however. We found that the critical role of delegated officer was not always held by a named officer who maintained regular contact with the person subject to the restrictions of the guardianship order. We do not consider this to be in line with the spirit of the legislation. Where a decision has been taken by the local authority to intervene in a person's life on a statutory basis, there should be a named delegated officer building a trusting relationship and ensuring that the order is meeting the person's outcomes in line with the principles of the Adults with Incapacity (Scotland) Act 2000 ('the AWI Act').

Recommendation 3: Community care review activity within Health and Social Care Partnerships should be dynamic, coordinated processes which include review of personal outcomes, care plans, placement, the guardianship order and whether all or some of the powers remain relevant.

Multidisciplinary reviews should be dynamic, coordinated processes informed by the principles of the AWI Act, maximising both the contribution of the person and their carers/relatives where appropriate. We found that reviews did not always focus on outcomes, the placement and the powers of the order. It is important to ensure that those involved are not passive recipients of information but have ongoing relationships that allow them to actively contribute to the review process.

Recommendation 4: Health and Social Care Partnerships' strategic advocacy plans should include focus on accessibility of advocacy support at all stages of the care and support continuum.

We have highlighted the challenges of supporting the rights of people with a diagnosis of ARBD to live as they choose balanced with their rights to access support to maximise their quality of life. The offer of advocacy support is an important safeguard to ensure respect for the rights, will and preferences of the person and not what is considered by others to be in that person's best interests. Advocacy support is important prior to the guardianship application stage, post guardianship and throughout the provision of continuing care.

Where recommendations are made to health and social care partnerships, this refers to the joint operational arrangements that exist in a council area between local authority social work services and health care services of the local health board.

Glossary

Advocacy
Advocacy means getting support from another person to help a person express their views and wishes, and to help make sure their voice is heard. Someone who helps an adult in this way is called an advocate

Care Inspectorate
The Care Inspectorate carries out joint inspections with other regulators to check how well different organisations in local areas are working to support adults and children. It helps ensure that social care services, including criminal justice social work, meet high standards. It also publishes inspection reports for every care service in Scotland.

CSWO
Chief Social Work Officer. The Social Work (Scotland) Act 1968 requires local authorities to appoint a single Chief Social Work Officer (CSWO) for the purposes of listed social work functions. The role provides strategic and professional leadership in the delivery of social work services.

HSCP
Health and Social Care Partnership. Whenever the term Health and Social Care Partnership or HSCP is referenced in the report, this refers to the joint operational arrangements that exist in a council area between the council social work services and the health care services of the local health board. All clinical, professional and support staff who work within a HSCP are employed by the health board or the council in the specific geographical area.

MHO
Mental Health Officer. An MHO is a social worker who has been qualified for at least two years before undertaking specialist mental health training which includes mental health law.

PoA
Power of Attorney – someone appointed by a person with capacity to make decisions about their welfare in the event that they lose capacity to do so themselves.

OPG
The Office of the Public Guardian in Scotland was created when the Adults with Incapacity (Scotland) Act 2000 received Royal Assent. It is a single information point about financial provisions contained in the Act.

s.47
Section 47 (AWI) Certificate issued by a doctor where the adult cannot consent to the treatment being given.

Welfare Guardian
A person appointed by the Sheriff Court to make decisions in relation to the welfare of a person who has been assessed as lacking capacity to make these decisions themselves.

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national
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