

## Chapter 4: The Role and Rights of Carers

### 1 What are your views on our proposals for mandatory Carer Awareness training for all mental health staff?

Please share your views on our proposals for mandatory Carer Awareness training for all mental health staff:

Carer Awareness training should be mandatory for all mental health staff and should include Neurodiversity training, to increase awareness of neurodevelopmental differences such as Autism, ADHD, Dyslexia, Dyspraxia etc. There is a need to consider carers' own needs such as processing and communication styles. This training should be continuous to keep mental health staff up to date with unpaid carers' rights. From our experience of providing training to GPs, we are aware that neurodiversity training is a gap in knowledge, even within health services.

### 2 What are your views on information sharing with unpaid carers of all ages?

Please share your views on information sharing:

Information sharing is a two-way process.

Mental health services should ensure that there is more information sharing with unpaid carers of all ages, and that the information is accessible to everyone including neurodivergent people. Information sharing with unpaid carers should be in the context of a human rights approach, which balances the rights of the person with lived experience and the rights of the unpaid carers. The rights of unpaid carers should be considered in human rights assessments.

People with lived experience of mental health issues often need representation. Unpaid carers often also need representation. These two representatives need to be separate and independent from each other.

Carers should be allowed to take part in tribunals, in order to ensure their rights are considered.

There should be an emphasis on the importance of the carer's role in the context of the carer's own human rights, their knowledge of the person's will and preferences, and their knowledge and expertise in communicating with the person.

In our experience of supporting parents and carers of family members experiencing mental health difficulties, if an unpaid carer is not represented by an advocate, then often the unpaid carer will not feel empowered to put forward their views and will not feel heard and understood.

Mental Health Services should focus on implementing the person with lived experience's will and preferences, in the context of the person's rights.

Decision making for adults based on 'best interests' should end. Information sharing with unpaid carers should therefore balance the person's will and preference and the unpaid carer's voice. However, this balance should ensure that unpaid carers receive adequate information to allay their concerns for their relative's wellbeing, even while protecting the person with lived experience's right to confidentiality.

If you are an unpaid carer, what are your views on sharing information with mental health practitioners?:

Although we are completing this as an organisation, some of our service-users who are parents or carers and who share information about their child with a mental health practitioner from CAMHS tell us that this information sharing has been crucial to them and to their child. It has provided a lifeline of support. One service-user reported that their relationship with the CAMHS worker encountered some difficulties due to a difference in opinion about PDA (Pathological Demand Avoidance). However, the fact that we provided advocacy for the parent, and could be a sounding board, improved the parent's relationship with the CAMHS worker. This helped the parent to work with the mental health professional to focus on what would work to meet the child's needs. The sharing of information between parents and carers and the mental health workers is crucial, but parents and carers often need support to be able to achieve this.

### 3 What is needed to ensure mental health services identify and engage with young carers?

Please share your thoughts on what is needed to ensure mental health services identify and engage with young carers:

Mental health services need to ask families and other professionals the right questions in order to identify young carers. The needs of young carers who are themselves neurodivergent should be met appropriately.

Mental Health Services need to have enough staff, all staff need appropriate training regarding young carers, and there needs to be a framework of relevant processes and designated time to engage with young carers.

For this to happen there needs to be sufficient resources allocated to Mental Health Services. A Human Rights Based Budget could provide a framework for this. (Ref: A. Flegg et al (2021) Introduction to Human Rights Budgeting with the Human Rights Budgeting Group. Together Scotland <https://www.togetherscotland.org.uk/media/2150/introduction-to-human-rights-budgeting.pdf> (Accessed 25/05/2022) )

There is a need for more understanding, awareness and support of sibling young carers and the caring experiences they have, as set out in the findings of the report Ask Me – I'm Here Too, a research and evaluation project into the lived experiences of young carers who are providing care for siblings with a long-term illness or disability. The eight recommendations in that report inform our following answer. (Ref: E Miller (2021) A Research and Evaluation Project into the Lived Experiences of Young Carers Providing Care for Siblings with a Long-Term Illness or Disability. University of Strathclyde and Edinburgh Young Carers. <https://www.youngcarers.org.uk/wp-content/uploads/2021/06/Ask-Me-Im-Here-Too.pdf> (Accessed 25/05/2022))

In our experience of supporting neurodivergent people and their families, there is a need for more understanding, awareness and support of

- young carers who are neurodivergent and / or
- young carers who are caring for someone who is neurodivergent.

and the caring experiences they have.

Mental Health Services need to be aware of the needs of Young Carers, including for many, a feeling of being ignored and of being voiceless and for some, having a parenting role. Mental Health Services should be aware that many Young Carers live in fear of bullying.

There is a clear need at a macro level for kindness and compassion to be adopted as organisational principles, across statutory and voluntary services in Scotland including Mental Health Services, particularly in the context of pandemic recovery. Information sharing about Young Carers is key. Where appropriate and with permissions, local authority Young Carers' Statements should be shared with Mental Health Services to further improve support and recognition. There is a need for a whole family focus, also promoted by The Promise, to be reflected in the respite, support and interventions of services with a remit for supporting children/families together. Mental Health Services and Carers Organisations should both adopt a trauma-informed approach, using national resources such as the Trauma Informed Practice Toolkit for Scotland by NES. Young Carers and Sibling Young Carers should be offered o more emotional support and, where required, therapeutic support through counselling or other mental health interventions. o dedicated and specific guidance and support at times of transition, especially around the transitions into young adulthood for themselves (and the cared-for sibling). Young carers also need to feel supported and empowered to engage with Mental Health Services and may often benefit from an independent advocate to support them to communicate with mental health services.

#### 4 What are your views on including unpaid carers in discharge planning and processes, as stated in Carers (Scotland) Act 2016?

Please share your views on including unpaid carers in discharge planning and processes, as stated in Carers (Scotland) Act 2016:

Neurodiversity should be considered in the discharge planning and processes. Those plans and process should take into consideration any neurodevelopmental conditions of the person with lived experience of mental health issues. The plans and processes should also take into consideration any neurodiversity of unpaid carers. Additional support should be put in place without delay. If the person with lived experience of mental health issues is neurodivergent then to ensure that their needs are met, there may need to be an enhanced planning process. Again, there should be no time delay. An enhanced planning processes may require even more involvement from unpaid carers, while considering the will of the person being discharged and any risks.

#### 5 What needs to happen to ensure unpaid carers of all ages are respected and valued?

Please share your views on what needs to happen to ensure unpaid carers of all ages are respected and valued:

Unpaid carers of all ages need to be considered, appreciated, heard and have the opportunity to have respite. The communication needs of unpaid carers should be recognised and respected. In the case of parents of children who are receiving mental health treatment, the support of carers' associations can be vitally important. Mental health service providers should be fully aware of carers' rights to support and should be able to make referrals to carers' support services. This could be a mandatory referral process, with an opt-out option. Consideration should also be given to situations where unpaid carers need specialist mental health support so that they can better support the person with lived experience: for example, specialist Family Support Workers attached to mental health services.

#### 6 Please tell us anything else you think may be relevant to the role of unpaid carers when supporting someone experiencing mental disorder and working with services.

Please share your thoughts:

In our experience, the mental health of unpaid carers can be put under severe strain due to their caring role, especially in times of crisis. Mental health service providers should be able to assess unpaid carers' support needs, and make appropriate referrals for support. The current situation of under-resourced services and 2-year waiting lists for CAMHS is unacceptable and is leading to more mental ill-health within families. If a child is not taking medication or receiving treatment, our experience is that CAMHS tend to discharge them after assessment, which puts unpaid carers under greater and continuing pressure. Critical mental health services need to link with other services that will provide support in such situations – our organisation is one such service.

#### 7 Please use the space provided below for any other comments you would like to make, relevant to this chapter.

Please use the space provided below for any other comments you want to make, relevant to [insert topic name].:

Neurodiversity, and communication needs for people who may be neurodivergent, should be considered when a framework is developed which encompasses best practice in identifying and working with carers of all ages and in improving communication in general.

## Chapter 9: Children and Young People

### 1 Do you think the current 2003 Act principle for children is still needed?

The current 2003 Act principle for children is still needed

Please explain your answer:

It is generally important to treat children differently from adults. Therefore, a distinct principle for children should be included in the Act. If the existing principle, and those of the UNCRC are both referred to, there could be an issue of interpretation because there will be both a 'welfare' principle and a 'best interests of the child' principle. Will either (or both) terms be defined? A secure legal definition, while potentially detracting from flexibility, would help to make rights meaningful and would aid their consistent application, as well as identifying when those rights have been breached.

Any reference to the UNCRC should be made in such a way as to recognise that the rights conferred by the Convention are legally enforceable by children.

2 What do you think about having a statutory duty on Scottish Ministers and health and care agencies to provide for children the minimum standards needed to secure the human rights set out in international treaties such as the UNCRC?

Please share your thoughts on a having a statutory duty:

UNCRC rights should, of course, be a minimum for children. However, it is important to ensure that children's rights can be enforced. It would be important not to reference minimum standards in any way that would detract from their enforceability. Enforceable rights should be spelled out in legislation. For example, the UNCRC right to education (Article 28) was adopted into Scottish legislation in the Standards in Scotland's Schools etc. Act 2000, which states in s1, "It shall be the right of every child of school age to be provided with school education by, or by virtue of arrangements made, or entered into, by, an education authority." (Ref: <https://www.legislation.gov.uk/asp/2000/6/contents> (Accessed on 26/05/22)).

In addition, the Supreme Court has recently questioned the legislative capacity of the Scottish Government to incorporate the UNCRC into Scottish legislation. As long as this issue remains contentious, there should be additional/alternative enforceable legal rights within the Mental Health legislation.

With regard to education specifically, access to education should be a continuing right for children. Local authorities have a duty to provide 'adequate and efficient' provision for additional support needs (ASN) under the Education (Additional Support for Learning) (Scotland) Act 2004, as amended. If detention or treatment under the mental health legislation were to qualify as an additional support need, the rights of children under the 2004 Act would be safeguarded. Currently, care experienced children are automatically deemed to have ASN, so there could be a similar provision in relation to detention under Mental Health legislation.

3 What are your views on reforming crisis services for children and young people experiencing acute mental distress?

Please share your views on reforming crisis services for children and young people?:

This is absolutely key. In our work with children who are neurodivergent, the failure to reflect and accommodate their specific neurodevelopmental condition(s) can lead to increased mental distress. This points to the need for mental health practitioners to be suitably trained in neurodiversity (in its broadest sense, and not just as it relates to autism).

The Promise Scotland is a programme to ensure that Children and Young people are not separated from their families. One of the 5 foundations of The Promise is 'Where children are safe in their families and feel loved they must stay – and families must be given support together to nurture that love and overcome the difficulties which get in the way.' Crisis services should be designed to work alongside, and not against, this key principle. A key consideration would be, how can crisis services be designed, trained, and resourced to support families to stay together safely rather than to remove children from their family other than when there is an issue of safety. These services should be equally available across Scotland, no matter where the family is located.

What are your views on the safeguards for emergency detention?:

The right to legal representation within 24 hours of emergency detention is essential, as is access to suitably skilled advocacy practitioners. Under no circumstances should emergency detention result in children being detained in adult accommodation.

4 What you think about law reform to ensure access to CAMH services up to at least the person's 18th birthday and to ensure age appropriate services more generally?

Please share your thoughts on law reform to ensure access to CAMH services up to at least the person's 18th birthday:

We believe that this is essential: CAMH services should be available to at least age 18. However, CAMH services are currently chronically over-stretched so this aspiration needs to be backed up by more resources: not just trained mental health professionals, but also allied health professionals and third sector providers.

Please share your thoughts on law reform to ensure age appropriate services more generally:

As above.

5 What are your views on our ideas about relatives and families?

Please share your views on our ideas about relatives and families:

Broadly, we agree with your proposals regarding relatives and families, subject always to children and young people's views being taken into account as a starting point. In our experience, parents and carers can sometimes be left out of decision-making, especially for older children including those aged 16 and older. However, in a crisis it is often the family who are called upon to step back in to provide support.

In addition, please see our response to Chapter 4.

6 What are your thoughts on how supported decision making, human rights enablement and the autonomous decision making test in chapters 3, 5 and 6 might apply to children and young people?

Please share your thoughts on how supported decision making, human rights enablement and the autonomous decision making test might apply to children and young people?:

Broadly, we support a human rights enablement approach. In considering the capacity of children and young people to make decisions, it is important that those acting in support or making the assessment have sufficient training and understanding to take into account any neurodevelopmental conditions, and how such conditions, or specific communication needs, might impact on decision-making.

## 7 What do you think about our proposals on advocacy and on accountability?

Please let us know what you think of our proposals on advocacy:

We support the view that there should be advocacy available to children affected by mental health legislation. However, to combine this with advocacy under education law, the benefits system and the Children's Hearings system is likely to result in one or two preferred providers being appointed to provide all advocacy to all children, restricting choice and the independent nature of advocacy services. For example, our organisation provides support and advocacy to any child who is neurodivergent, irrespective of diagnosis. Over many years, we have developed enormous expertise in working with these children. However, we are likely to be priced out of competitive tendering against larger organisations that have less specialist knowledge of neurodiversity. Therefore, while we support the principle that advocacy should be available, we urge that this is not provided in a way that restricts choice or special expertise.

It is important that children affected by mental health law are able to access non-instructed advocacy, where appropriate. This is especially important for children with neurodevelopmental conditions, who may be non-verbal.

Please let us know what you think about our proposals on accountability:

## 8 What are your views on autism, learning disability and neurodiversity and the possible law reforms for children and young people?

Please share your views on autism, learning disability and neurodiversity and the possible law reforms for children and young people:

The time is ripe for law reform that fully accounts for neurodiversity. We agree that to include learning disability and autism within the definition of 'mental disorder' is offensive and outdated and the shift in emphasis proposed by the review - from mental disorder to impaired autonomous decision making - is a better approach.

Neurodiversity is poorly understood as a concept – often it is used as a synonym for a neurodevelopmental condition such as autism or ADHD. However, neurodiversity is a broader concept that refers to “the diversity found in all human brains and minds – the infinite variation in neurocognitive functioning within our species.” (Ref: Nick Walker: <https://neuroqueer.com/neurodiversity-terms-and-definitions/> (accessed on 25/05/22) ). Great care must be taken to ensure that by incorporating neurodiversity into, or aligning it with, mental health law, the natural occurrence of neurodiversity is not reframed as a mental health 'issue': around 15% of the UK population is neurodivergent. (Ref: <https://www.local.gov.uk/lga-libdem-group/our-press-releases/neurodiversity#:~:text=However%20it%20is%20estimated%20that,learns%20and%20processes%20> (Accessed on 24/05/22).) Some of that population also experience mental illness. The focus of the proposed shift from mental disorder to a human rights enabled approach and a well-informed understanding of the concept of neurodiversity can and should help to protect the rights of people who are neurodivergent within the mental health system.

## 9 What do you think about our proposals on safeguards for treatment and services, and safeguards to protect the relationships between children and parents?

Please share your thoughts on our proposals on safeguards for treatment and services:

We would recommend that Mental Health Officers who are supporting neurodivergent children should have adequate training in neurodiversity to ensure that their professional decision-making takes full account of the impact of neurodivergence upon children and their families.

Please let us know what you think about our proposals to protect the relationships between children and parents:

We agree that it is necessary to consider how to protect relationships between parents and children. We note that The Promise Plan 21 -24 opens with the statement – “There will be deliberate, persistent attention to upholding safe, loving relationships that are important to children and young people.” (Ref: <https://thepromise.scot/> (Accessed 24/05/2022)). Any reform of mental health law should be consistent with the outcome of the Care Review and The Promise that resulted.

## 10 At this time, Scotland's mental health law applies to compulsory mental health treatment at all ages. Do you have views on the idea of moving mental health law for children to connect it with other law for children, to apply across health, education and social care?

Please share your views on the idea of connecting mental health law for children with other law for children:

Mental health law for children should interact well with other areas of law, such as health, education, social care and justice. The full recognition of children aged 16 and 17 as 'children', as defined by the UNCRC, would be a key starting point in such a shift. In addition, we note the increasing recognition that the human brain continues to develop until at least age 25 (Ref: O'Rourke et al (2020) The development of cognitive and emotional maturity in adolescents and its relevance in judicial contexts. Scottish Sentencing Council. <https://www.scottishsentencingcouncil.org.uk/media/2044/20200219-ssc-cognitive-maturity-literature-review.pdf> (Accessed 24/05/22)), and the changing science around brain development should be taken into consideration in reform of the law. There is a gap between children's and adults' services and the transition between the two is often very poorly managed – young adults can fall through the net. Services should be joined-up to avoid poor transitions, which can be damaging to the mental health of those involved, and law reform should be enacted in such a way as to minimise the risk of poor transitions from childhood to adulthood. The availability of advocacy, including non-instructed advocacy, should be included within all areas of the law for children. Where non-consensual treatment is appropriate and unavoidable, it should be for minimal periods only, with full clinical oversight and stringent risk assessments and review. Non-consensual treatment should be clearly defined to include treatment other than medication, so that all interventions are

subject to the same safeguards, risk assessments and review.

11 Please use the space provided below for any other comments you would like to make, relevant to this chapter.

Please use the space provided below for any other comments you want to make, relevant to [insert topic name].:

In addition to the specific issues addressed in our response, we would urge the review team to ensure that reform of the law is matched by the expertise and resources to avoid an implementation gap. Scotland has much excellent, human-rights based, legislation and policy (in education for example) but all too often there is not sufficient resourcing to ensure that the public bodies who should fulfil the legislative obligations can deliver the services needed. This results in a lack of accountability (and consequent redress) and erosion of rights.

## Independent Individual Advocacy

### 1 What is the current landscape and how can we improve it

Please share your thoughts on this proposal:

In general, consolidation of the law can help to simplify a complex legal landscape. Consistency can also help to overcome a postcode lottery of services. However, there is a risk of monopolies of suppliers and restriction of choice if over-regulation results. Our answers to the following questions have been formed to take this consideration into account.

### 2 Improving access to independent advocacy

No

Please give reasons for your answers:

Advocacy should empower individuals to fully participate in decisions and to be heard. It should ensure individuals are aware of all options, can make informed decisions and can exercise choice and control over their circumstances. An opt-out system may impair the level of choice and personal agency by adding perceived pressure to engage in advocacy or by reducing choice over which agency is providing the opt-out service. That said, advocacy should be far more widely available and it should be essential that individuals are made aware of advocacy, its purpose and how to access it.

Please give your views on our suggestions for change:

We would broadly agree with the proposals for change. However, a legal definition of advocacy and central commissioning requirements could have the unintended consequence of over-regulation and restriction of choice.

### 3 Evaluation and Quality assurance of Independent advocacy organisations

Please give us your views on the proposals for evaluation and quality assurance of independent advocacy organisations:

Salvesen Mindroom Centre has robust monitoring and evaluation processes in place and takes seriously its responsibility for maintaining a consistently high quality of support across services, including advocacy for unpaid carers and children and young people. This level of reporting and evaluation is also a requirement for most funding bodies. There is the risk that the introduction of a formal body may duplicate reporting requirements already in place for funders and could detract from limited resources available for providing advocacy.

In particular if you consider the role of evaluation should be given to an existing body, we would welcome suggestions as to which body might take on that role.:

### 4 Who can be an independent advocate?

Please give us your views on our proposals for who can be an independent advocate.:

There are challenges in the consideration of the term "independent advocate". Currently to be registered as such with the SIAA, the organisation must not provide any additional services such as training or advice services, even within different sectors of the organisation. Membership of the SIAA is sometimes a requirement in public procurement contracts. This therefore has the potential to exclude organisations who are providing high-quality advocacy. There should be greater flexibility in the consideration of "independent advocates", perhaps in assessing potential conflicts of interest rather than blanket exclusions.

It is essential that advocates have a strong understanding of rights, legislation and policy, and are skilled in working in a person-centred way. Values and personal qualities can be just as important as knowledge. This is unlikely to be captured within a specific qualification.

There are particular training courses which are essential within our organisation, such as Child Protection and Equality and Diversity, as well as key internal policies and procedures which are in place and regularly reviewed. This good governance supports our ethical advocacy practice.

The current advocacy qualification is prohibitively expensive and would detract from the resources required to deliver advocacy. The requirement to have a specific qualification before entering the workforce could exclude the majority of talented individuals. Perhaps guidance on training or free/cost effective e-modules to ensure advocates are aware of the key principles and ethos of independent advocacy and basic knowledge requirements would be more appropriate than a qualification itself.

Please also let us know if you consider the qualifications and registration should be required for those who support collective advocacy groups:

### 5 Diversity, equality and inclusion

Please give us your view on our proposals for improving diversity ,equality and inclusion in independent advocacy :

As a general principle, we support diversity, equality and inclusion. This helps to ensure that individuals have sufficient choice to meet their needs and preferences.

### 6 Funding and commissioning of independent advocacy

No

Please give reasons for your answers:

Although we support the recognition that more funding for advocacy is a pressing concern, we have answered No to this question for the following reason:

There should be far more resource and funding for the provision of advocacy, however it is essential that this does not exclude those who fall outwith the definition of "independent advocates" as referenced above. Current tenders/funding bids can favour the same few organisations and there may be concerns that a national fund would be largely directed to these organisations, rather than available across the sector. Should this fund replace other funding opportunities, this would reduce choice for individuals and may actually restrict the availability of advocacy.

#### 7 The role of independent advocacy in supported decision making

Please give us your views on the proposals for training and your reasons for these:

All advocates should have knowledge of human rights and individual legal rights. Salvesen Mindroom Centre uses a mixture of training/reading/research through induction and beyond to support individuals to develop this knowledge, but the skills in this area are better developed through quality supervision and support, building on a foundation of knowledge.

#### 8 Scrutiny/accountability of Independent Advocacy Organisations at a strategic level and at a micro level

Please give us your views on our proposals for scrutiny of independent advocacy organisations:

Salvesen Mindroom Centre takes pride in providing high quality support. Evidence of our standards and practice are also required by funders. There can be variation in how different organisations work and this can promote choice for individuals who may prefer one approach to another. However, all organisations offering advocacy should be working in line with general principles of advocacy, so this should be considered within scrutiny. The introduction of any scrutiny body should not detract from existing resources available to provide advocacy.

#### 9 Independent advocacy for carers

Please give use your views on the proposal for support for unpaid carers. :

We would agree that organisations should be funded to provide advocacy for unpaid carers. Salvesen Mindroom Centre have a service for parents and carers of neurodivergent children but there is considerable demand for this support. Advocacy for unpaid carers can make all the difference to the success of interventions - well-supported carers are themselves in a better position to give support to their family member in need of mental health care or treatment.

#### 10 Do you have additional proposals for change?

Please let us know of any other changes you think are needed.:

It can take time for a neurodivergent person to build the trusting relationship needed to support meaningful advocacy. If there is a step in a legal process that introduces the right to independent advocacy, timescales should be flexible enough to ensure that this relationship can be successfully established.