



Response from the National Carer Organisations to  
“Consultation on Learning Disability and Autism in the Mental Health Act”

### **About the National Carer Organisations**

The National Carer Organisations are brought together by a shared vision that all Scotland’s unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Trust Scotland, the Scottish Young Carers Services Alliance, Carers Scotland, the Coalition of Carers in Scotland, Shared Care Scotland, Minority Ethnic Carers of Older People Project (MECOPP and Crossroads Caring Scotland).

### **Overview**

Carers Trust Scotland, on behalf of Scotland’s National Carer Organisations, undertook the process of consulting with carers of people with autism and/or learning disability who have experience of using Mental Health (Care & Treatment) (Scotland) Act 2003, or are aware of it. The following is a breakdown of how this was done.

- Lanarkshire – September 2019 – group of 5
- Renfrewshire – September 2019 – group of 4
- Dumfries & Galloway – October 2019 – group of 5

Telephone consultations were also carried out during September/October 2019 with 7 carers (1 carer from Inverness; 2 from Perth; 1 from Glasgow; 1 from Borders) and telephone consultation in October with 2 carers (Dumfries and Galloway).

The feedback is set out to correspond with specific questions set within the main Review document (these are in yellow boxes), plus there is some additional information for Review team to consider towards end of document.

### **Consultation**

#### **1. What Scotland needs to do**

We think that Scotland’s mental health law needs to change for autistic people and people with learning disability.

We think that the law needs to change to comply with the United Nations Convention on the Rights of Persons with Disabilities.

We also think that it needs to change to comply with the European Convention on Human Rights in full.

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Feedback from all carers spoken with confirm the view now taken by National Carer Organisations that Scotland's mental health law needs to change for autistic people and people with learning disabilities. Over half the carers consulted with felt that mental health law, as it stands, did not comply with United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) or European Convention on Human Rights (ECHR).

The carers consulted felt that the current mental health law did not consider the varied factors that underpin a diagnosis of learning disability or autism and confused behaviours with signs/symptoms of mental illness.

The National Carer Organisations wish to see a change in Scotland's mental health law which respects the rights of people with learning disabilities and autism in line with UNCRPD and ECHR.

### **2. How we understand autism, learning disability and mental health**

We suggest that Scotland needs to move to understanding autism and learning disability as disabilities, not as mental disorders.

We think that Scotland's mental health services for autistic people and people with learning disability need to move to a human rights culture.

In Scots law, everyone is presumed to have legal capacity. We suggest that it should not be possible to challenge the legal capacity of autistic people or people with learning disability.

All carers spoken with, either face to face or via telephone, objected to learning disability being included as a mental disorder. A quarter of the carers found it difficult to understand how learning disability could be classed as a mental disorder when the learning disability is not something likely to be cured and doesn't always mean the person with experiences any mental illness, stress or distress.

A further quarter of the carers felt that learning disability was used to meet the test of mental disorder where the behavior of individual was especially challenging and support and/or services were unable to help, or more usually such support provision was not available.

*"It's as if we are expected to cope with behavior which is challenging, but when you ask for more help there's nothing there. That's when they mention the Act and a possible solution to be sectioning him [carer's son]."* **Carer, Renfrewshire**

The above view was echoed by three quarters of the carers we consulted with

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*“They don’t have the money to provide the safe services folk need so they just section them and put them in these horrible places”* **Carer, Dumfries & Galloway.**

*“It’s the lack of money for social care and day activities which causes frustration and carer burnout. I’ve had to give up work so I can be there for her [carer’s sister] because her day place was removed. When she gets so frustrated the social worker says she’ll get an MHS [Mental Health Officer] to come and see about using the law.”* **Carer, Glasgow**

We agree that Scotland needs to move to understanding autism and learning disability as disabilities not as mental disorders.

When participants were shown the definition of disability used within the Convention on the Rights of Persons with Disabilities<sup>1</sup> all agreed that this, or something similar should be used within Mental Health Act. Definition:

‘Disability results from the interactions between persons with impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.’

The National Carer Organisations agree that the above definition, or something similar, should be adopted within Scotland’s mental health law in relation to people with autism or learning disability. When viewed in this manner, we feel that Scotland can move away from seeing learning disabilities and autism as disorders which can be treated medically; and towards an understanding of them as disabilities. This is especially important given that learning disabilities nor autism have no medical ‘cures’.

### 3. Support for decision making

We suggest that Scotland should make change to comply in full with a key right in the Convention on the Rights of Persons with Disabilities, the right to equal recognition before the law.

To make it possible for autistic people and people with learning disability to have and use their legal capacity, Scotland would have to give strong support for decision making. We make a range of suggestions on how this support should be set up.

We also discuss how we think decisions should be made on psychological interventions, psychotropic medication, and at times of crisis.

<sup>1</sup> Convention on Rights of Persons with Disabilities, United Nations, 2006

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The National Carer Organisations agree that full support should always be given to people with learning disabilities or autism to make decisions affecting their care and treatment.

We agree that such support should be offered from a variety of sources, including independent advocacy, unpaid carers, and decision supporters.

The carers consulted as part of this review also agreed with the idea of changing the use of Advance Statements for people with learning disability or autism and moving towards a statement of rights, wills and preferences.

In Scotland all adults are deemed to have legal capacity<sup>2</sup> when aged 16 or over. In order to ensure this, carers agreed that people with autism and/or learning disabilities may require additional support to make certain decisions. In fuller discussions with carers all agreed that supported decision-making processes should be available to enable anyone to make decisions.

Attention must be paid to a person's will and preferences and all carers involved felt that this could be a vital role for carers to play as many of them are aware of the preferences of the person they care for. The reality can be different though.

*"Sometimes you feel as though they [services, both health and social care] just don't listen. They always think they know best. We've lived with our son for 24 years they've only cared for him [in hospital or respite] for about 2 years [carer counted number of times in care or respite]. How can they know what he likes or doesn't like or want or doesn't want? But then who are we?"* **Carer, Renfrewshire**

The above quote is not unfamiliar to any of us within national carer organisations. A couple of carers on the telephone felt that those in power who make decisions about care and treatment should move away from the notion of doing it in the 'best interests' of the person. The carers felt this was patronising and denied the individual the right to make mistakes or take risks. A better way the carers suggested was to make decisions with the person.

All carers acknowledged that decisions made by other people (where a person is unable to assert their decisions even when assisted) must respect the will, preferences and rights of the individual unable to make such decisions.

### **Role of Independent Advocacy**

National Carer Organisations recognise the importance of all people with learning disability or autism, regardless of age, having the right to access independent advocacy. To do this would require adequate funding to ensure such services exist.

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<sup>2</sup> Age of Legal Capacity (Scotland) Act, 1991, Section 1.

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We agree that right to such service should be on an opt-out basis.

We also agree with the need for non-instructed advocacy as a means of moving away from the overly paternalistic ‘best interests’ approach currently used. In this situation the non-instructed advocate (who could be the person’s unpaid carer) gives the ‘best interpretation’ of the persons will and preferences. Carers who were consulted were very much in favour of this, but also stressed that to do that they would need to be identified and valued as carers.

*“It’s so frustrating that you are not even talked to. Our son was detained last year and although we had a say at the Tribunal on the ward it was a different story. They just did not value what we had to say about what our son likes or doesn’t like. It was very much ‘we are the experts we know what to do’. Hate to tell them they are not the experts on my son!”* **Carer Lanarkshire**

The National Carer Organisations support the acknowledgement given by the Review team of the possible need for an independent review to consider the role of unpaid carers in law in Scotland. Given the uncertainty over the role of named person, particularly where a professional does not think the person is able to choose a named person.

The National Carer Organisations along with carers consulted as part of this review, agree that the human rights assessment approach must consider the right to family life for all involved with the person with learning disability and the person with autism.

It is vital that unpaid carers also have access to independent advocacy to assist them to continue to provide care. At present such access is very limited across Scotland and no area of legislation covers the need to provide or right to access independent advocacy for carers. Very often carers are asked to give their views or find themselves in the positions of challenging professional decisions. This is a daunting process for many carers who may be experiencing trauma and stress during or following a period of crisis. Being able to access independent advocacy can help to reduce the impact of caring and support the carer to make the best choice available to them to continue to provide care and have a life alongside caring.

We strongly agree with the Review findings that carers may separate, independent representation to protect their rights.

### **Decisions on psychological interventions, psychotropic medications and at times of crisis.**

When the role of the mental health tribunal for Scotland (used to determine need for detention, amongst other issues) was explained all carers felt that the specific forms

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of treatment, whether that be prescribing medication, psychology or other forms of care and treatment should be agreed to or not on an individual basis.

Carers felt this would make it more transparent and person with autism or learning disability could object to some of the treatment or support. A few carers made the point that actual medical treatment may not be needed but that support is required. *“My son didn’t take any medicines and they weren’t going to give him any, what he needed was to be in a place which had routine and structure and would keep him safe. He needed to know there were support staff there that’s what helped.”* **Carer, Borders.**

*“We the family all felt he didn’t need to be detained in a hospital, he needed to be in a home that had been adapted to suit his needs and had staff to help him, that would have been much better. Putting him in hospital and at times having to restrain him, has set him back a few years. It’s awful.”* **Carer, Renfrewshire.**

### 4. Support, care and treatment

We suggest that autistic people and people with learning disability should be given rights in law to have access to the support, care and treatment that they need.

We also make suggestions on how support, care and treatment could be provided for women, children and offenders, in ways that respect human rights.

We discuss some duties that would need to be placed on public authorities to make these rights real.

The National Carer Organisations agree that Scotland needs to give autistic people and people with learning disabilities clear rights of access to the support, care and treatment that they need.

Most carers consulted as part of this Review, agreed that people with autism and people with learning disabilities should have the right to health. A fundamental part of this is the provision of regular health checks. Some of the carers consulted felt angry that this was not done on any kind of routine basis.

*“When my daughter turned 16 all routine health checks stopped, she was seen as an adult (or at least that was how we felt) and so could make her own appointments for health checks. She isn’t able to do that and it’s just another thing we carers have to remember to do.”* **Carer, Borders**

A third of the carers consulted agreed with the Review findings that health and social care environments could do more to support a person with autism. All the carers who commented on this were carers of people with autism. It was felt that some settings are unsuitable for autistic people and so can exclude them from accessing

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vital health checks or make the situation very stressful which the carer and family then are left to deal with.

*“My brother hates going to the GP. He likes his GP as she is friendly and takes her time with him, but it is the waiting room he hates. It’s too bright, too noisy and he must wait ages to be seen. I’ve tried to explain this to receptionist and practice manager, but I don’t get anywhere, the usual answer is ‘we are a very busy practice maybe he could sit in the car until it is his turn’ how stigmatising is that?”* **Carer, Perth**

We agree that autistic people and people with learning disabilities not only need regular health checks but that these checks need to be in environments suited to need and carried out by professionals with appropriate skills and training.

### Other Considerations during Consultation

The above areas were discussed in association with the Review findings survey, but we also discussed issues around detention and criteria for deciding detention.

### **Mental Health (Care & Treatment) (Scotland) Act 2003: Test 3 for making a compulsory treatment order: Significant Risk if treatment not available**

All carers felt that this was usually confused with the person being ‘dangerous’ and none of the participants agreed with this.

*“Just because he is autistic does not mean he is dangerous or violent. If you know how to deal with him, what to say, how to approach him etc, he is perfectly calm. Problem is they [services] just don’t listen to what I’m telling them.”* **Carer, Lanarkshire**

Three-quarters of participants did express the need for the law to be clear about what is meant by risk and look at separating this out from a risk of causing harm to self or others, and a risk to the individuals rights. The participants felt that if risk was present because treatment was not available, then the onus is not on the person with autistic or intellectual impairment, but on the lack of environmental or cultural supports to prevent disability from occurring.

*“They said that my sister was a danger to herself and others cause she kept hitting her head on the wall and then hitting out at staff, therefore she passed the risk test. What they didn’t listen to was us saying that her behaviour was as a result of being in a room she didn’t like; she can’t speak so that was how she communicates. So-called professionals disagreed with us, so she was sectioned.”* **Carer, Glasgow.**

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### **Mental Health (Care & Treatment) (Scotland) Act 2003: Test 5 for making a compulsory treatment order: The making of an order is necessary.**

Carers were informed of the principles underpinning Mental Health Act<sup>3</sup> the principle of reciprocity, which states

'Where society imposes an obligation on an individual to comply with a programme of treatment and care, it should impose a parallel obligation on the health and social care authorities to provide safe and appropriate services, including ongoing care following discharge from compulsion.'

The carers all agreed that this should be a very important aspect of making the decision whether a compulsory treatment order is necessary. It may be that, for some people with autism or learning disability, the issue which is causing difficulties is more of an environmental one and carers could not see how this would make it necessary to detain someone rather than making it an order that health and social care services provided the most appropriate environment for the individual's needs.

All carers agreed that decisions made about detaining a person with autism or learning disability should be proportionate as well as necessary. It may not be necessary to detain someone in hospital, for example, if appropriate supports were put in place. As with one of the examples given above from a carer if the correct housing option was in place for her sister, then detention would not have been necessary.

### **Limitations to Consultation**

Due to time constraints and number of carers taking part, it was not possible for us to discuss specific issues. During the consultation the following areas were not considered:

- Women
- Children
- Offenders
- Role of Tribunal and other professionals

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<sup>3</sup> Mental Health (Care&Treatment) (Scotland) Act, 2003, amended in 2015, Parts 1-3

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## Conclusion

The National Carer Organisations welcome this Review and support its recommendations, in relation to changing how Scotland views autism and learning disability.

We support and congratulate the Review in making the case for a more rights-based approach to be taken within mental health legislation which reflects the principles of United Nations Convention Rights of Persons with Disabilities and European Convention on Human Rights.

It is encouraging to see the valuable role of unpaid carers being recognized within this Review and wholeheartedly support the need for such carers to be listened to, supported and empowered to play as active a part in decision making with the autistic person and person with learning disability. We would have liked to have seen more mention made to the role of young carers and sibling carers within the Review but respect the limitations of the Review.

We believe that unpaid carers of all ages need to have a legal right to access independent advocacy. This legal right would recognise that unpaid carers often have different needs from the person they are caring for and may need the additional support of independent advocacy to help them know and understand their rights, identify their options and make informed decisions.

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This feedback is submitted on behalf of Scotland's National Carer Organisations by Karen Martin, Mental Health Coordinator, Carers Trust Scotland.

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