



Key and Community Lifestyles

Our response to the findings and recommendations of the Independent Review of the Mental Health Act (IRMHA)

About Key and Community Lifestyles

We provide high quality person centred support to over 2000 disabled people and people with long term conditions across Scotland.

Our vision is that disabled people in Scotland are living the lives they choose, close to their family and friends, connected to their communities as equal citizens.

Our mission is to be alongside each person we support, empowering them to lead their life to the full and play their part in society. We are passionate about providing the very best quality support.

The Review

We welcome the opportunity to revisit the scope of the Mental Health (Care and Treatment) (Scotland) Act 2003 and how it applies to people with learning disabilities and autistic people.

The review's clear emphasis on human rights and ensuring these are brought to life for people with learning disabilities and autistic people is something we strongly support. As is how comprehensively the review has considered the evidence it has drawn from individuals, families, professionals and academic sources.

We welcome how far-reaching the review's scope is and the fact that it has not shied from considering how the recommendations could impact upon, and require the review, of other relevant legislation, such as the Adults with Incapacity (Scotland) Act 2000.

A number of specific recommendations are particularly welcomed:

- We believe it is right that learning disability and autism are not considered mental disorders.
- The suggested shift towards a model which acts upon the rights, wills and preferences of individuals rather than decisions being made in their 'best interests'.
- The recommendation that people can develop their own 'Statement of rights, wills and preferences' in a form which is accessible and meaningful to them.

- The suggestion that it should not be possible to legally challenge a person's capacity. We understand this will have huge implications for guardianship under the Adults with Incapacity (Scotland) Act 2000, however it is our experience that some supported individuals are not always fully aware of the rights they cede whilst subject to guardianship measures.
- The acknowledgment of the high use of psychotropic medication among people with learning disabilities and autistic people, and how this is often inappropriately used to modify behaviours rather than to treat a diagnosed mental health condition. We agree that a national review is required.
- We welcome the focus on advocacy and supported decision-making. We believe it is right that people have access to independent advocacy in their lives and note the review's acknowledgement of the current under-funding and stress on existing services.

There are a number of recommendations about which we have particular comments to make.

Definition

The disability model definition adopted within the review is not, we feel, fully consistent with the social model of disability and thus allows for that possibility for people with learning disabilities and autistic people to continue to be detained and compulsorily treated as result of impairment rather than society's response to it.

Supported decision making

We would urge clarification on the different roles that could become a 'decision supporter'. For every person who needs this support with their decision making we should recognise how that person comes to be in the individual's life, the power dynamic which exists between them, any pre-existing relationships and the potential for conflicts of interest. There is also a need to ensure that 'decision supporters' are not viewed as an alternative or replacement for independent advocacy.

Human rights assessments

We are unclear as to the value of 'human rights assessments', this is not something which would be offered to others who do not have a learning disability or autism. We would argue that if the right support has gone into the person developing their 'statement of rights, wills and preferences', and is utilised in a similar way to

'advance statements' then it could be possible to avoid a further layer of bureaucracy which is not directly derived from the person's wishes. We would also be concerned that this be carried out by a Mental Health Officer who may not know the person well enough and could present a potential conflict of interest if decisions are made around resource concerns rather than finding more community based solutions to support the person's distressed state.

Specialist health and social care services and environments

We found the recommendations within this section of the review to be at odds with the direction of travel of social and health care policies since the early 2000's. The publication of 'The same as you?' in 2001 made clear the wishes of generations of people with learning disabilities and autistic people that they wanted support to lead good lives in their own homes, and in communities where they could enjoy connections with family, friends and neighbours. 'The keys to life' then moved this agenda on by acknowledging the continuing difficulties people with learning disabilities and autistic people face in accessing the right support, the need for more co-ordinated cross governmental policy making and recognised that there was still much to be done in people being able to play their full part in society.

Furthermore the creation of more specialist services and housing options seems inconsistent with promoting the choices and human rights of people with a learning disability and autistic people. It could, indeed, be viewed as undermining the long-fought rights of people with learning disabilities and autistic people to access mainstream services with the right person centred support which respects and encourages their own choices and control over their lives. The suggestion also contradicts the principles of the Self-directed Support (Scotland) Act 2013 and the ability for people to exercise choice and control over their lives, who they live with and how they are supported.

We also know through 'The keys to life' and other sources that many people still face often unacceptable levels of discrimination and difficulty in accessing and receiving treatment from health services. We therefore believe that creating a separate parallel system suggests that people's needs can sometimes be just too difficult or different for our healthcare staff to treat. We would also suggest this approach would undermine efforts to build the skills, knowledge and capacity of the NHS and its staff in providing excellent quality health, including mental health, services to people with learning disabilities and autistic people.

We were particularly, and deeply, concerned about the suggested establishment of 'secure support centres'. It was clear from the Scottish Government's 'Coming Home' report that people with complex needs, learning disabilities and autistic people are too often supported in resources far away from their families and communities. There is a concerted strategic effort to actively find community based solutions which enable people to return from out of area placements to live their lives, reconnected with their friends, families and communities.

It is unclear from the review as to the model of support and treatment that would be adopted in such settings. There would also be considerable financial implications to creating these settings. Over and above these concerns though is a fundamental unease about this approach and we would point to evidence uncovered about the experiences of former residents of Winterbourne and Whorley Hall whose human rights were often badly abused in such settings.

We are grateful for the chance to offer some of our thoughts on the review and would be willing to discuss these with, or support, the review team further with understanding our work and approach.