

SWAN - response to Stage 3 consultation document IRMHA October 2019

Dr Catriona Stewart

Firstly it is important to acknowledge the commitment and hard work demonstrated by the Review Team. I also personally wish to thank you for the way you have conducted the process of the commission in terms of your commitment to genuine inclusion of the autistic and learning disabled lived experience perspective along with all other 'stakeholders'. Reconciling all of these must be a complicated and difficult task but you seem to be creating something that is highly constructive and positive. Establishing a human rights foundation from the start I perceive has helped to create what could be described as a cultural scaffolding to the project, and that human rights perspective been reflected throughout the course of the review.

It has been a privilege to be involved; there has been challenge and robust debate (I don't think that anything truly important doesn't involve these things) and so much that has been positive and encouraging. I have learned an enormous amount through this process. I was moved too, after years of speaking, at presentations and training sessions, on human and citizen-rights, laws not being implemented, the need to facilitate, and listen to, the authentic voices of lived experience - to hear those things and the need for these to be addressed, clearly articulated in this context.

Thank you!

1. Definitions and terminology

Terms such as disability, deficit, disorder and impairment trigger very varied responses. The overwhelming response to our initial invitation through the SWAN network to input into our organisational response to the review was that autism should be removed from the category of 'mental health disorder'. The recommendation, to do this and to instead consider autism within UN definitions of 'impairment' and 'disability', is welcomed with some discussion and caveats.

The term impairment is a tricky one, and there are differences of opinion within the SWAN participant population about the appropriateness of this term.

Some people identify with the term disabled, and some don't. Some people may be OK with the term impairment, others may not be.

There is disagreement as to whether people feel they are impaired all the time or not. Some people feel they are impaired all the time, others do not.

"Impaired" suggests global negativity. This interpretation is potentially emotive: these definitions are not neutral, but impact on core senses of identity and self-worth.

However there is also understanding that terms used within the recommendations of this review - and not just the terms, but the intention and context within which they are being used - need to correspond with international existing human rights legislation.

Having said that there is also discretion that can be used in individual nations, and this is something for the review team to consider.

There is recognition that definitions can be important to enable people to access support including financial support.

Could it be possible to say "a person is autistic at all times and this includes impairments and strengths"?

It is also important to distinguish between how terms are used in the community and in law: currently autism is defined within a medical model as a mental health disorder, both in the USA (DSM V) and in Europe (IDC 11). However, defining autism as a mental health disorder in law - or not - is a national choice.

It is acknowledged that the proposed definition of impairment and disability could take autistic people out of a mental health model and towards a social model, which we enthusiastically welcome.

2. Services

For the law to be affective, appropriate services need to be available for autistic people. They need to be consistent, reliable, autism-informed and easy to access.

3. Accountability

In all of this accessible accountability is key - otherwise any new law may not be implemented properly, as happens with existing laws. There are laws in place to protect children, on education, on equality and discrimination and so on but so often these are not implemented adequately. Any legislation must be supported by clear routes to accountability and remedy. It must be easy for autistic people to hold professionals / services accountable.

4. Direct involvement of autistic people and DPOs

The direct involvement of autistic people in all aspects is crucial, including delivery of services, training etc.

In every aspect of the mental health process, including autistic people as advocates, advisors to professional, trainers to the service personnel is essential for effective, appropriate delivery.

For example, if the first point of contact for staff of a service for autistic people is other autistic people, this could help to provide insight and learning, to overcome myths and stereotypes. In other words, we need to ensure that all professionals and services are informed by the lived experience perspective and kept up-to-date with current learning. Currently so much training is out-of-date, ill-informed and potentially damaging.

We agree that in order to ensure the points above, DPOs need to be properly resourced.

5. Gender: diagnosis and decision-making

We agree with the importance of consideration of gender in diagnosis and decision-making, in every aspect of the process and delivery. We also would raise that that consideration may include awareness that many autistic people have personal issues around gender and sex identity.

We emphasise that those considerations and decision-making processes must include the perspectives - and knowledge base - of those who are well informed in this area, which might well mean autistic women, or well-informed professionals or both (and in some cases, specific individuals will be both!).

There are particular problems with access to appropriate diagnosis for women at the moment. Getting a diagnosis can depend on luck, having the right professional involved etc. Many women are currently not diagnosed but still experience the difficulties being autistic may bring in specific situations and contexts.

There is concern that there is a drive not to diagnose people because then there is a duty to provide care and a lack of resources to do so. Some local authorities have explicitly

chosen to only provide a route to a diagnostic assessment where there is a diagnosable mental health illness or disorder as well - the system is geared towards promoting crisis.

6. Safe places and secure support centres

The name “secure support centre” could be confusing at best and off-putting at worst.

We agree it would be very beneficial to have somewhere to help people heal, rather than make things worse. A “Maggie’s Centre” for autism, staffed by autistic people. An alternative comparison might be something akin to a Women’s Aid refuge, again with an emphasis on peer support and informed care.

We need to stop funding services that are designed to only ‘manage crisis’ and that often only exacerbate the problems. We need services that intervene at a preventative level to support people. The financial case for investing in preventative/inter-departmental/evidence-based support and services is made in the UK-wide National Autism Project’s The Autism Dividend report, published 2017. There is also the Scottish Microsegmentation Report, published this year, which is incomplete (it ignores the hidden population of autistic women - and some men, who also cannot access diagnostic services in some areas - and so its analysis in terms of gender is flawed) but which still lays out the financial impact of current approaches to autism service provision.

7. Human Rights Assessments

Concern that the “what’s possible” aspect of this process of decision-making could lead to the same problems being experienced due to lack of resources.

E.g. a tribunal could say “we cannot allow this person to fulfil their rights, will and preferences because it is not possible to do so due to resources”.

8. Professional roles

“Care Coordinator” could be a good term for the “care manager”.

With regards all roles the importance of training and understanding is paramount. Otherwise there will still be bad decision-making. There needs to be autistic input to this training. The quality of training varies at the moment.

9. A new law

Agree that there should be a new law.

This could include a Commissioner for autism.