

Meeting with ELAS 24 October 2019 10-11am

Notes of comments made by members of ELAS.

Decision-making and capacity

For someone with autistic disability, capacity should include capacity to give consent.

Where there is a directly declared intention of suicide this is obvious, so there is no objection there to decisions being made for a person.

Certainly not where there is just a doctor's judgment of there being a suicide risk.

When it is more about life choices and decisions, for an autistic person who can speak in full-meaning language, can fully understand language and has got nothing applying against their capacity, the idea that autism in itself could be grounds to have the person's choice over-ridden, there is a negative assumption in there that autism is a lower status or mental status. Legal capacity limits should be defined without a different reference to autism.

This is in reference to people with full understanding and not those with further intellectual impairment.

(Simon explained that this is not possible legally to remove detention on the basis of disability until the UN clarifies its position and the European Court of Human Rights changes its position, however, a contact in mental health interest, with some knowledge of this law area, has offered a conflicting opinion:

That article 14 of UNCRPD includes "the existence of a disability shall in no case justify a deprivation of liberty". That in 2014 the office of UNHCHR issued a statement on this article 14, that it asserts an "absolute prohibition of detention on the basis of disability". Making this an already clarified line from the UN. That on 19-3-19 when minister Clare Haughey announced a broader review of the whole of mental health law, she mentioned that it will take account of developments since the present act came into force, and there referred explicitly to UNCRPD).

The best way to cover ourselves is to write references to the relevant conventions into our reports, so that the interpretation of the report is tied to these conventions.

There is support for the “rebuttable presumption”.

How professionals make decisions

Are we referring to disability which affects people’s life decision processes? What other sort of disability could be used to justify compulsion?

(Simon gave example of someone experiencing extreme distress due to changes in circumstances)

Wherever compulsion is to be used the person needs to be able to express their will and preferences to someone who is not going to be responsible for their compulsion. The person needs to be independent and be bound by confidentiality. This is in case there is a difference between their actual will and preferences and what they might feel they have to say to the responsible professional in order to get the best out of the situation.

It would be important that there was no conflict of interest for the advocates. It is important for the advocates not to be doing other things they can be in conflict with the person about, for example collective advocacy as exemplified by the case described in Autism Network Scotland's book *An Ordinary Life Too*, which is an autism strategy guide document, chapter 12.

Monitoring decisions

Anyone making decisions in particular should be accountable to the parties they affect. It must be challengeable at some level.

There should be guidelines against deciding on grounds just of caution to continue and prolong detention situations instead of reach an ending for them.

Involvement of DPOs

Any autistic organisations might have something to say and new organisations might emerge. Membership of committees should be open. It shouldn’t be a situation where there are certain seats to fill, a tick box. Once these roles are full they don’t change and so views are not representative. It needs instead to be open access. As organisations respond they should be entitled to take part, even conflicting ones, so that they can get their oar in.

Where support takes place

There are lots of stories and petitions about people placed in care a long way from their families and families taking a long time to get them out again. It is good that our ideas are aiming to prevent that.

Offenders

Why would it just be offenders for whom there is a presumption that they would not go to hospital? Why not everyone with autism or learning disability?

The law

Regarding requiring standards on information from professionals to support decision making; professionals need to give the person information about the specific autistic difficulty that is influencing the professional's decisions, thus making it open to be challenged. Decisions need to be explained and transparent.