

Accessing formal support through the lifespan

A presentation at Autscope 2014 by Yo

0 – 25 years

Now

- Separate: Statements of Special Educational Needs (SEN) + Social services care plan + individual health services (and usually no coherent plan)
- Transition from child to adult services a chaotic mess

From September 2014

- Combined: Education, health and care plans (EHC plans)
- Combines SEN statement with social services provision and health provision
- Only for those who have current SEN statement or Learning Disability Assessment (in college) or would qualify under same rules. So if no SEN, no EHC plan. In theory could still get some social services provision under
- Procedure for transition from child to adult services laid out and should be clearer and smoother

18+

(includes 65+, but this group sometimes treated as 'older adults' and denied access to what few autism-specific services there are)

Now

- Community Care Assessments under the 'Fair Access to Care' guidance (FACS)
- In most council areas, only 'substantial' or 'critical' levels of need qualify for support
- Eligibility focussed on your ability to maintain independence
- Person assessing you *should* have had autism training (but hard to enforce)
- *Any* disability qualifies (you do not need to 'fit' into one of the teams or categories that your local social services use – but councils routinely break the law and tell you that you do)
- Little or no access to advocacy services
- Direct payments widely available but 'all or nothing' and admin requirements large
- Rigid, arbitrary rules about what 'care' you can buy
- Care is not free. Means tested charging.

From approx. April 2015 onwards

- Care Assessments under the Care Act 2014
- National eligibility criteria, but local councils will still vary in how they interpret them
- The levels of need which will trigger access to formal support are going to be broadly similar to those which apply now (and quite high)
- Eligibility focussed on your “wellbeing” (not “independence”)
- Person assessing you *should* have had autism training (still quite hard to enforce)
- *Any* disability qualifies (you do not need to ‘fit’ into one of the teams or categories that your local social services use – but it is likely that councils will continue to routinely break the law and tell you that you do)
- Promising advocacy rights
- Virtual right to direct payments and possible to have partial direct payments and more support with the admin (though there still may not be autism appropriate support available)
- Much more flexibility about what ‘care’ you can buy
- Care is still not free. Means tested charging still applies and may not be any fairer. And there may be charges for advocacy.

Qualifying for formal support under the new system (probably from April 2015 onwards)

Short version

You need to show that:

- because of a disability
- you have a LOT of difficulty with at least one of:
 - looking after yourself (or a child if you are a parent)
 - maintaining basic, essential social relationships (eg with your family)
 - accessing any meaningful activity (eg voluntary work, studying)
 - accessing services in the community (eg GP, leisure activities)

AND

- that this is having a negative impact on your wellbeing

Long version (you have been warned!)

- Probably need a diagnosis/support from a doctor (as now)
- There must be a *significant impact on your wellbeing* as a result of being unable to do one of the things below. This depends on what YOU consider important to your wellbeing (so if you say that you don't care whether you have any friends, being isolated may not count)
- Being unable* to achieve any ONE of:
 - (a) carrying out some or all basic care activities (eating and drinking, maintaining personal hygiene, toileting, getting up and dressed, getting around your home; preparing meals and cleaning and maintaining your home) – Note that you need to be unable to achieve **some or all** – so **one** will not be enough. Also note that taking medication, staying safe and being independent are **not** on this list!
 - (b) maintaining family or other significant personal relationships;
 - (c) accessing and engaging in work, training, education or volunteering;
 - (d) accessing necessary facilities or services in the local community including medical services, public transport, educational facilities, and recreational facilities or services;
 - (e) carrying out any caring responsibilities the adult has for a child.

*Unable means

- (a) is unable to achieve it without assistance;
- (b) is able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;
- (c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or
- (d) is able to achieve it without assistance but takes significantly longer than would normally be expected.

For those interested, “wellbeing” is defined as relating to any of:

- personal dignity (including treatment of the individual with respect);
- physical and mental health and emotional well-being;
- protection from abuse and neglect;
- control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- participation in work, education, training or recreation;
- social and economic well-being;
- domestic, family and personal relationships;
- suitability of living accommodation;
- the individual's contribution to society.

How to challenge decisions under the new systems

0-25 EHC plans

Education part only – appeal to tribunal (as now for statements)

Health and Care parts – can only make a complaint or apply for a judicial review

18 + Care Assessments under the Care Act

The Care Act contains provision for direct appeals of care plans BUT this would have to be brought into force by the government and it **doesn't** look like that is going to happen.

So (as now) you can only make a complaint or apply for a judicial review

Making a complaint

See my 2009 Autscope presentation 'Using complaints to improve services' for general guidance.

BUT important to understand that complaints can ONLY fix problems with the council getting its procedures wrong (eg refusing to assess you). A complaint WON'T get the council to give you different (or more) support than they are offering.

Applying for Judicial Review

If you think your council has gone seriously wrong in handling your case, then go to a *specialist* solicitor (in social care law – you can look this up on the Law Society website) and get advice about applying for a judicial review. You CAN get legal aid to do this.

BUT important to understand that a judicial review will ONLY be effective in cases where a council has:

- ignored the law
- behaved so unreasonably that it could be called irrational
- violated your human rights

If you just don't like what they are offering you, **legally** isn't very much you can do about. However, in my experience, making **effective** complaints CAN help in achieving better support simply because the council will sometimes give in to get you to stop hassling them!