Where next for autism policy and practice?

On 4 February, Dimensions convened its first Autism Summit. 60 expert delegates including many self-advocates contributed to discussions covering autism friendly environments, hate crime, the language we use and autism policy and practice.

Discussions on autism policy and practice focused on the government's strategic autism theme of **"Making sure autistic people get help in their communities."** They resulted in the following set of policy recommendations, which we are sharing with the government's Autism Strategy Executive Group and the APPG on Inappropriate Institutional Care. Notes from the full discussion are appended for context.

Policy recommendations

1. Fix the numerous perverse financial disincentives to discharge, for example the settings of the dowry system, through a full review of the financial structures associated with transforming care. Money should never be a reason for keeping a person locked up.

2. No ATU should be able to score better than inadequate in a CQC inspection if more than (x) patients are missing an in-date CTR.

3. No ATU should be able to score better than inadequate in a CQC inspection if more than (x) in an inspected sample are considered to fail quality parameters.

4. Every CTR to identify locally present organisations with experience of supporting people out of ATUs.

5. An outright ban on for-profit organisations running ATUs.

6. Strengthen family information networks through funding independent advocacy groups.

7. Increase funding to the Disabled Facilities Grant, extending maximum funding beyond the current £30k limit for people in exceptional situations - and commit to this in the long term.

8. Commit funds to specialist housing development in line with forecast long term demand

9. Require a proportion of 'social housing' in mainstream developments to include restricted funding for alterations to meet individual accessibility requirements

10. Fund social care in line with the Local Government Association's (or similar) assessment of need.

Appendix: Workshop notes

1. Strategic context

Context for this paper is given by the Autism Act 2009 and the national autism strategy 2021-2026, together with its associated delivery plan and commissioning guidance aimed at 'levelling up society' and 'building back better.' Progress is due to be monitored by an autism strategy executive group, comprising experts by experience.

The strategy consists of six key themes. This workshop focused exclusively on one of those themes: **"Making sure autistic people get help in their communities."**

The government's 2026 vision for this theme is to:

- Achieve stated transforming care targets by 2024.
- Modernise the MHA: autism alone to no longer be a lawful basis for detention.
- Improve the provision and quality of community support, including social care, mental health and housing, to prevent crisis.
- Inpatient settings [to be] high quality, therapeutic and tailored to [people's] needs, and as close to home as possible.

And in year 1 the government aims to provide:

- £25m to improve the capacity and capability of 7-day specialist multidisciplinary learning disability services and crisis support
- £15m for keyworkers for children with complex needs, including autism
- £18.35m to prevent crises and avoidable admissions, improve care for autistic people in inpatient mental health services and facilitate discharges
- £21m to local authorities through the Community Discharge Grant
- A formal response to the Mental Health Act consultation

As preliminary remarks, we noted that:

- The most recent autism strategy executive group meeting was cancelled for lack of any progress to report
- The funding equates to £0.5m per local authority. Many individuals in ATUs cost more than this each year.

2. Building the Right Support

This is the NHS Plan to transform care for people in, or at risk of entering, long stay hospitals.

In 2015, the plan set an ambition that:

- "Overall, 35% - 50% of inpatient provision will be closing nationally with alternative care provided in the community…"

- "In three years we would expect to need hospital care for only 1,300-1,700 people where now we cater for 2,600..."

In 2019 that target was backdated to 2024 for lack of progress. The human impact of this is measured in terms of wasted lives. In 2021:

- More than 2000 people spent Christmas locked up in an ATU
- For 6 in 10 of those, this was at least the second consecutive locked-up Christmas
- 100 people have spent more than 10 years locked up in an ATU

But progress has been made:

- 2065 people were recorded as being in an ATU at end Dec 2021, down from 2900 in 2015. (This number will rise somewhat as many commissioners report late.)
- However at face value, that's a 40% reduction, within the target %.
- Within this, **a 48% reduction in inpatients with a learning disability (only) diagnosis contrasts sharply with a 55% increase in inpatients with an autism (only) diagnosis.**

Other data illustrates the growing problem with how we support autistic people:

- 6 out of every 7 people under the age of 18 admitted to ATUs now have autism and no learning disability.
- If you have an autism-only diagnosis in an ATU, you are far less likely to have a discharge plan in place than if you have a learning disability (22% vs 30%.)
- The proportion of inpatients with an autism-only diagnosis has risen from 16% to 34% in the past 6 years

If the acid test of Transforming Care is 'what are providers doing?' then there is space for concern. A report by the Challenging Behaviour Foundation, Mencap and Learning Disability England tells us that:

- Some providers are investing, not divesting
- NHS Provider Collaboratives include discredited providers
- Private hospital providers are developing residential care to which they discharge their own patients.

Many are now also being designated as failing by CQC and closed to new patients but with no alternative provision being put in place.

3. Policies to tackle the problem

Dimensions has put forward 7 policies to tackle this entrenched problem. In our workshop we discussed these, and other policy options, in detail (notes follow later.) The seven policies include:

1. Fix the perverse financial disincentives to discharge by reducing the health dowry to 2 years.
2. Statutory fines if any inpatient lacks an in-date Care & Treatment Review including discharge plan.
3. Every CTR to identify local organisations with experience of supporting people out of ATUs.
4. An outright ban on for-profit organisations running ATUs.
5. Strengthen family information networks through funding independent advocacy groups.
6. Invest in the specialist housing market; housing is cited as the major barrier to discharge.
7. Fund social care in line with the Local Government Association's assessment of need.

3.1 Fix the perverse financial disincentives to discharge by reducing the health dowry to two years

NHS(E) specialised commissioning / CCG funding is available for life once the person has been in hospital for 5 years.

For those being discharged sooner, commissioning guidance states that "Local Authorities will need to agree their own contribution." We're very far away from accusing LAs of reluctance to support someone out of hospital before the 5-year mark on financial grounds, but every possible disincentive must be eliminated.

We observed that:

- The system works best when strong leaders are in place who can override the constraints of the system in the interests of the person
- There are numerous financial disincentives to discharge patients and a root-and-branch review of these would turn up more than just the dowry issue

We now propose the following policy:

- **Fix the numerous perverse financial disincentives to discharge, for example the settings of the dowry system, through a full review of the financial structures associated with transforming care. Money should never be a reason for keeping a person locked up.**

3.2 Statutory fines if any inpatient lacks an in-date Care & Treatment Review including discharge plan

Everyone entering an ATU should have a pre-admission CTR or, if that is not possible, one should be established within days. All CTRs should be reviewed every 6 months. All should include a discharge plan. No discharge plan, no discharge.

The data shows that for too many people, CTRs are not happening. Taking the most recent data available from NHS Digital – fewer than 1 patient in 4 is getting a CTR within 3 months of admission despite guidance stating they should be in place within 15 days. This is not good enough but there is no sanction. Overall fewer than 1 in 3 people (31%) have a discharge plan in place

We observed that:

- The problem is real but the solution may not only lie in sanctions.
- Fundamentally this is a compliance concern that should be monitored by CQC
- There is also a problem of quality – too many CTRs are delivered with the wrong people present and without the right information available.

We now propose the following policies

No ATU should be able to score better than inadequate in a CQC inspection if more than (x) patients are missing an in-date CTR.

No ATU should be able to score better than inadequate in a CQC inspection if more than (x) in an inspected sample are considered to fail quality parameters.

Clearly, work is required to define x.

3.3 Every CTR to identify locally present organisations with experience of supporting people out of ATUs

We also hear repeatedly that CTR participants don't believe there are organisations in the neighbourhood capable of supporting complex individuals. We respectfully disagree; Dimensions alone covers half the country and there are many other providers with comparable skills. The ATU may not provide a list but commissioners could; local offer websites could also be strengthened.

We observed that

- Some Local Offer websites are restricted to locally-based (as opposed to locally present) providers; this should change.

We did not amend this policy proposal

3.4 An outright ban on for-profit organisations running ATUs

A responsible clinician – the hospital doctor responsible for assessing a person as fit for discharge – may be under undue commercial pressure when making this assessment.

Equally, where the pressure to discharge becomes too great to resist, there will always be ways to keep a person within the ATU's sphere of control for longer. Step down units, linked care homes, 'supported living' units in the grounds… all these and more techniques are in regular use to protect profits.

Until we remove the profit motive, there will always be pressure to keep a person within the system, and keep the money rolling in.

We did not amend this policy proposal

3.5 Strengthen family information networks through funding independent advocacy groups.

Families can play possibly the biggest role of all, but too many are isolated and lack the knowledge to press for discharge effectively.

Family networking has been hobbled by the loss of the National Valuing Families Forum and similar. How much does it really cost to run a nationwide family support forum like this? How powerful could the information sharing be? It has to be independent; Dimensions can't do it. But we reckon that it could be funded for a fraction of the annual cost of keeping 1 person locked up.

We observed that

- Some families are exhausted and will not proactively reach out. Networks need toplay a proactive role in offering support
- This has to be a strictly informal networking group – it does not replace direct family involvement in their relative's support
- Forums are well placed to share anonymous stories to help (not beat up) commissioners

We did not amend this policy proposal

3.6 Invest in the specialist housing market; housing is cited as the major barrier to discharge

Lack of suitable housing provision is cited as the key factor in almost 50% of delayed discharges.

We know we need more specialist housing and we know we need more funding to adapt housing to meet individual needs.

On the latter point, we're pleased that the Disabled Facilities Grant was extended in the most recent social care white paper.

We're pleased, too, that £300m was earmarked for specialist housing. £300m sounds like a lot. But according to one government study, demand for supported and specialist housing is rising by 125,000 units this decade. To achieve that, either government will build at a cost of just over £2k per house, or at a fractionally more realistic cost of 50k per house, we'll build just 1% of the number needed. It's great that government has recognised the problem; now we need to fund it properly.

We observed that

- If we want society to be truly inclusive for everyone, housing developers need to include more accessible (as opposed to 'social' housing in their developments.
- Unsuitable housing is a leading cause of unsafe discharges
- The speed of grant funding presents a further barrier to discharge

We now propose the following policies

- Increase funding to the Disabled Facilities Grant, extending maximum funding beyond the current £30k limit for people in exceptional situations - and commit to this in the long term.
- Commit funds to specialist housing development in line with forecast long term demand
- Require a proportion of 'social housing' in mainstream developments to include restricted funding for alterations to meet individual accessibility requirements

3.7 Fund social care in line with the Local Government Association's assessment of need

The LGA is well placed to articulate what local government needs in order to deliver the great social care that will prevent admissions in the first place. The LGA estimates a current gap of 7.3-8.1bn:

- 1.5bn (fair price of care – older people)
- 1bn – pay parity w nhs
- 3.2bn – unmet demand (older people)
- 1.6bn (unmet demand, working age adults)

We observed that

- There's also an argument for an independent body to be set up to determine social care funding needs – is the LGA perceived as a pressure group?

We now propose the following policies

- Fund social care in line with the Local Government Association's (or similar) assessment of need.

4. Wider policy discussion

Who is responsible for the success or failure of Transforming Care? Everyone and no-one. We believe there's an accountability and leadership vacuum.

- Policy proposal: Create a new role: "National Director for Transforming Care."

Much of the narrative in this debate relates to accelerating change. But sometimes, the pressures have resulted in unsafe discharges; we must recognise that these are complex situations and not simply focus on discharges; unplanned readmissions are also a key measure.

It is not immediately obvious to MPs that some of their constituents are bound up in this (though often will be living Out Of Area), nor that they have ATUs in their constituency. We should help match ATUs to their constituency MPs so that MPs can monitor and encourage progress at a local level.

The Mental Health Act Consultation received a government response in August. That response included the following: "We intend to bring forward a Mental Health Bill, which will give effect to many of the changes we wish to make, when parliamentary time allows." We must continue to press for parliamentary time.

5. Influencing change

As Barbara Keeley announced, a new APPG on 'Inappropriate Institutional Care' will be set up to elevate the issue and press for changes. Dimensions will provide the secretariat and we believe that APPG will be the most effective route to presenting these policy proposals.

We must work in partnership with those who have done so much work in this area already; the Winterbourne families and Rightful Lives were cited, and many organisations have their own policy proposals in this area. We must come together, under the umbrella of the new APPG, and speak with a single, louder, voice.