dimensions

Broken systems broken lives

11 policies to limit ATU admissions and accelerate discharges

"With appropriate resourcing, legal frameworks and genuine co-working between agencies, families and the person, people can live in the community to achieve their potential.

"If at all, hospital should only ever be one small step in a pathway.

"For the pathway to avoid dead ends, it must include person-centred philosophy, trauma-informed planning and practice, targeting resources to prevention and removing the opportunity to profit from institutional care."
Jeremy Tudway, Clinical Director, Dimensions

1 In a nutshell...

Funding

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.

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

Care and Treatment Reviews

3. No ATU should be able to score better than inadequate in a CQC inspection if more than 10 % of patients are missing an in-date CTR.

4. No ATU should be able to score better than inadequate in a CQC inspection if more than 10 % of an inspected sample are considered to fail quality parameters.

5. Every CTR must identify locally present organisations with experience of supporting people out of ATUs.

Profit motive

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

Families

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

Housing

8. 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.

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

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

Accountability and progress

11. Create a new role: National Director for Transforming Care

You can now help by:

- Writing to your constituency MP and asking them to join the new APPG on Inappropriate Institutional Care

- Writing to us and lending you and your organisation's support to the policies: marketing@dimensions-uk.org

2 Background

2.1 Building the Right Support (2015)

In 2015 the NHS published its strategy to cut ATU inpatients, it was called 'National plan - Building the right support'. It had some big aims. By 2019…

- "Overall, 35 % - 50 % of inpatient provision will be closing nationally with alternative care provided in the community…"
- "We would expect to need hospital care for only 1,300-1,700 people where now we cater for 2,600..."

That 2019 deadline got pushed to 2024 due to lack of progress. That delay is best framed, we believe, in wasted lives. Now, seven years on and with two years left on the revised clock, we still haven't seen the reduction in numbers planned:

- More than 2000 people spent last 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.

2.2 Inpatients by assessed need

The number of people in ATUs fell from 2900 in 2015, to 2135 at the end of 2021, a fall of 26 %. Far from on track, but not negligible progress either.

Another picture emerges from the detail, however. The number of people in an ATU with a learning disability has almost halved, yet the number of those with an autism-only diagnosis has increased dramatically. Now:

- 6 out of every 7 people under the age of 18 admitted to ATUs 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

This is steadily becoming an autism and youth dominated problem.

2.3 What are providers doing?

The acid test of the ambition to reduce the number of inpatients is to look at what private providers are doing. And we're seeing investment, not divestment, in bed spaces. Indeed, nearly half of all inpatients are now in private hospitals to which NHS targets do not apply.

NHS Provider Collaboratives include numerous hospital providers; community providers are rarely represented. For example the IMPACT collaborative in the East Midlands, including Elysium, Cygnet, the Priory and St Andrews.

Organisations are playing with language. Cygnet are marketing a new locked 'step down' model that is open to new referrals – any meaningful distinction, for a newly referred patient, is hard to fathom.

And a report from Mencap, the Challenging Behaviour Foundation and Learning Disability England states that private hospital providers are developing residential care to which they discharge their own patients.

At the same time, many are also being designated as failing by CQC – ironically even as pressure to close beds increases, we see a crisis around bed availability. This is a broken system.

3 Where do we go from here?

So many organisations – we might mention Rightful Lives and the Winterbourne Families amongst many others – have and continue to do so much good work to press for change. Nothing in these policy proposals contradicts or undermines their bodies of work. We must come together and speak with a single, louder, voice.

Dimensions is currently supporting the launch of a new APPG on Inappropriate Institutional Care, to be chaired by Barbara Keeley MP. Our shared aim is to build parliamentary awareness of people locked away in and out of MPs constituencies, and to provide constructive solutions

These policy proposals have come from extensive work with experts from across the sector including numerous experts by experience. Taken together, we believe these policies will unstick the transforming care agenda:

3.1 Funding

- 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.

Current policy contains numerous perverse financial disincentives to discharge. One example is that 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."

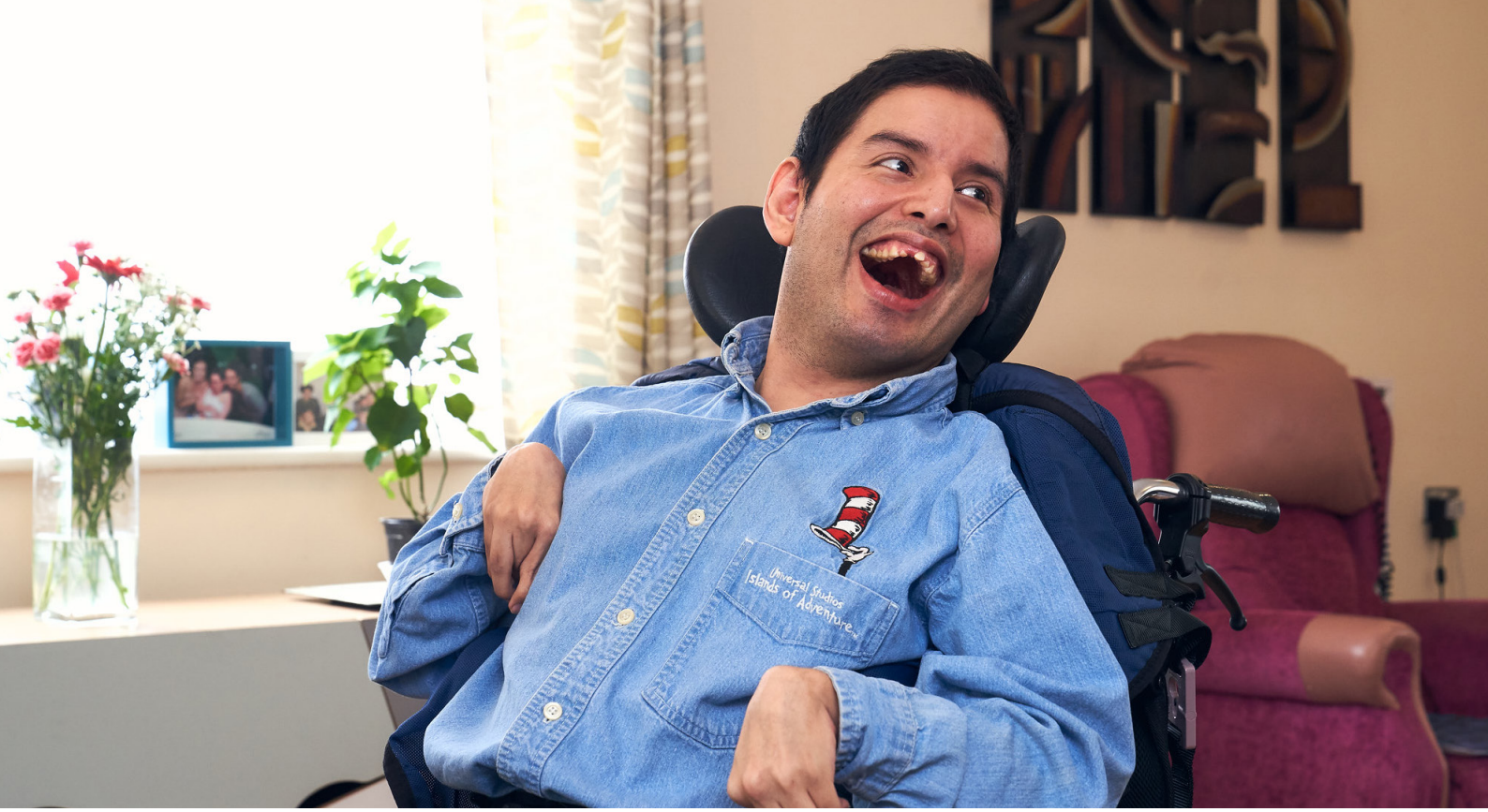
We're very far away from accusing LAs of reluctance to support someone out of hospital before the 5-year mark on financial grounds but every possible disincentive must be eliminated through a full review of the financial structures associated with transforming care.

- Fund social care in line with the Local Government Association's (or similar) 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 £7.3-8.1 billion, broken down as follows:

- £1.5 billion - Fair price of care for older people
- £1 billion – To bring social care pay parity with the NHS
- £3.2 billion – To cover the unmet demand for older people
- £1.6 billion – For the unmet demand of working age adults

Some argue that the LGA is a pressure group; there is therefore also an argument for an independent body to be set up to determine social care funding needs.



3.2 Care and Treatment Reviews (CTRs)

- No ATU should be able to score better than inadequate in a CQC inspection if more than 10% of patients are missing an in-date CTR.
- No ATU should be able to score better than inadequate in a CQC inspection if more than 10% in an inspected sample are considered to fail quality parameters.
- Every CTR must identify locally present organisations with experience of supporting people out of ATUs.

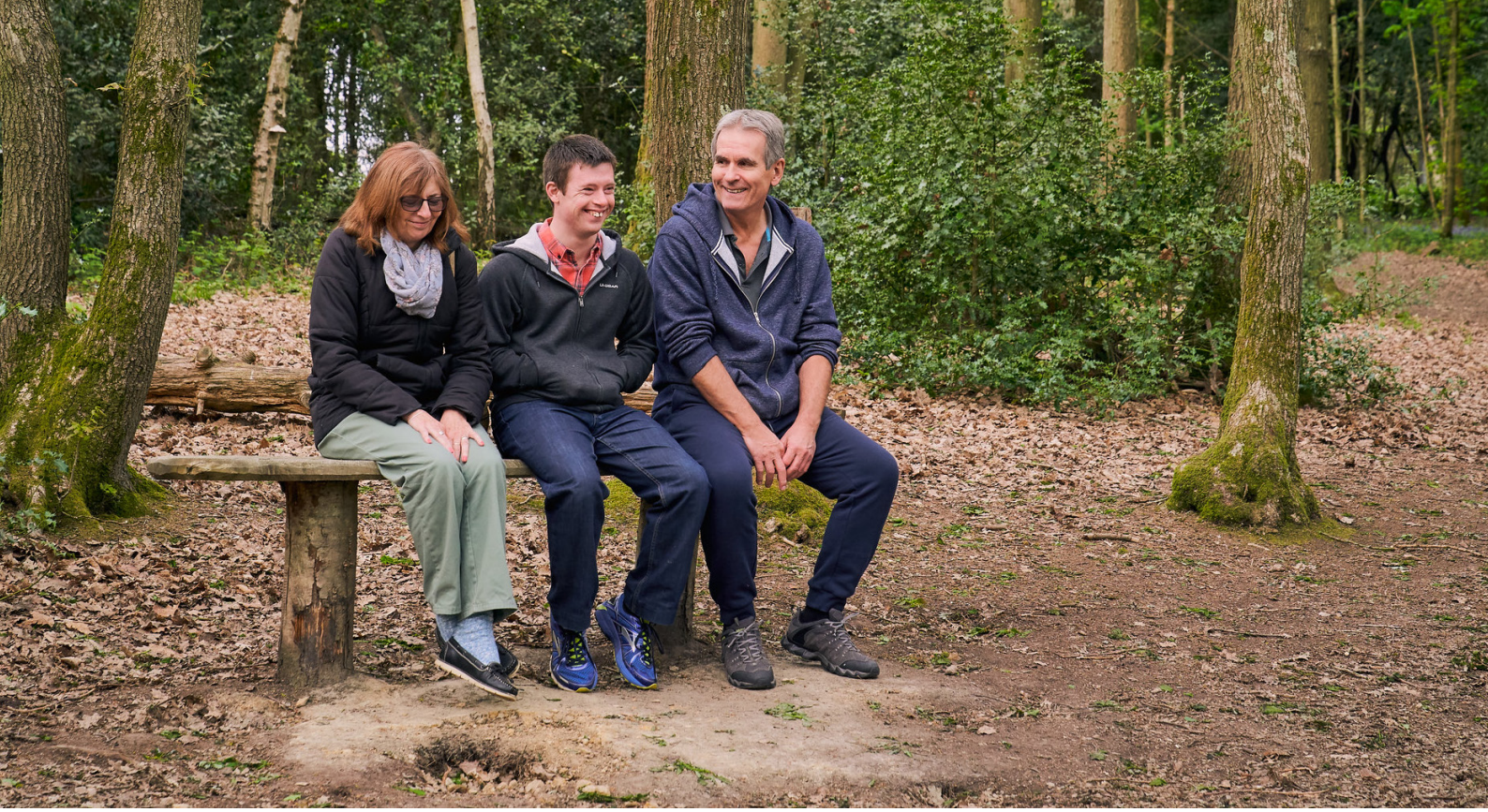
Everyone entering an ATU should have a pre-admission CTR or, if that is not possible, one should be established within days. All CTRs should be reviewed every 6 months. All should include a discharge plan. Because of course in the absence of a discharge plan, there is little chance of a discharge.

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

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. Again, we believe CQC must have a role in quality checking CTRs.

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



3.3 Profit motive

- Implement an outright ban on for-profit organisations running ATUs.

Those who work for or commission into for-profit ATUs may be uncomfortable this. But there is no choice. The harder the NHS works to close bed capacity, the more the private sector simply expands to fill the gap.

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

And where the pressure to discharge becomes too great to resist, there will always be ways to keep a person within the private provider'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.

3.4 Families

- 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 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 fully funded for a fraction of the annual cost of keeping 1 person locked up.

We know that some families are exhausted and will not proactively reach out. Networks need to play a proactive role in offering support, operating as a strictly informal networking group without replacing direct family involvement in their relative's support.

Forums are also well placed to share anonymous stories to help support commissioners.

3.5 Housing

- 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.

Lack of suitable housing provision is cited as the key factor in almost 50 % of delayed discharges and unsuitable housing is a leading cause of unsafe 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. But the speed of grant funding presents a further barrier to discharge

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, it'll build just 1 % of the number needed. It's great that government has recognised the problem; now we must fund it properly.

Finally, 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.

3.6 Accountability and progress

- Create a new role: National Director for Transforming Care

Who is responsible for the success or failure of Transforming Care? Everyone and no-one. There's an accountability and leadership vacuum. That's why we're proposing a new role, National Director for Transforming Care.

Fundamentally the role is to influence the system in pursuit of these policy proposals.

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.

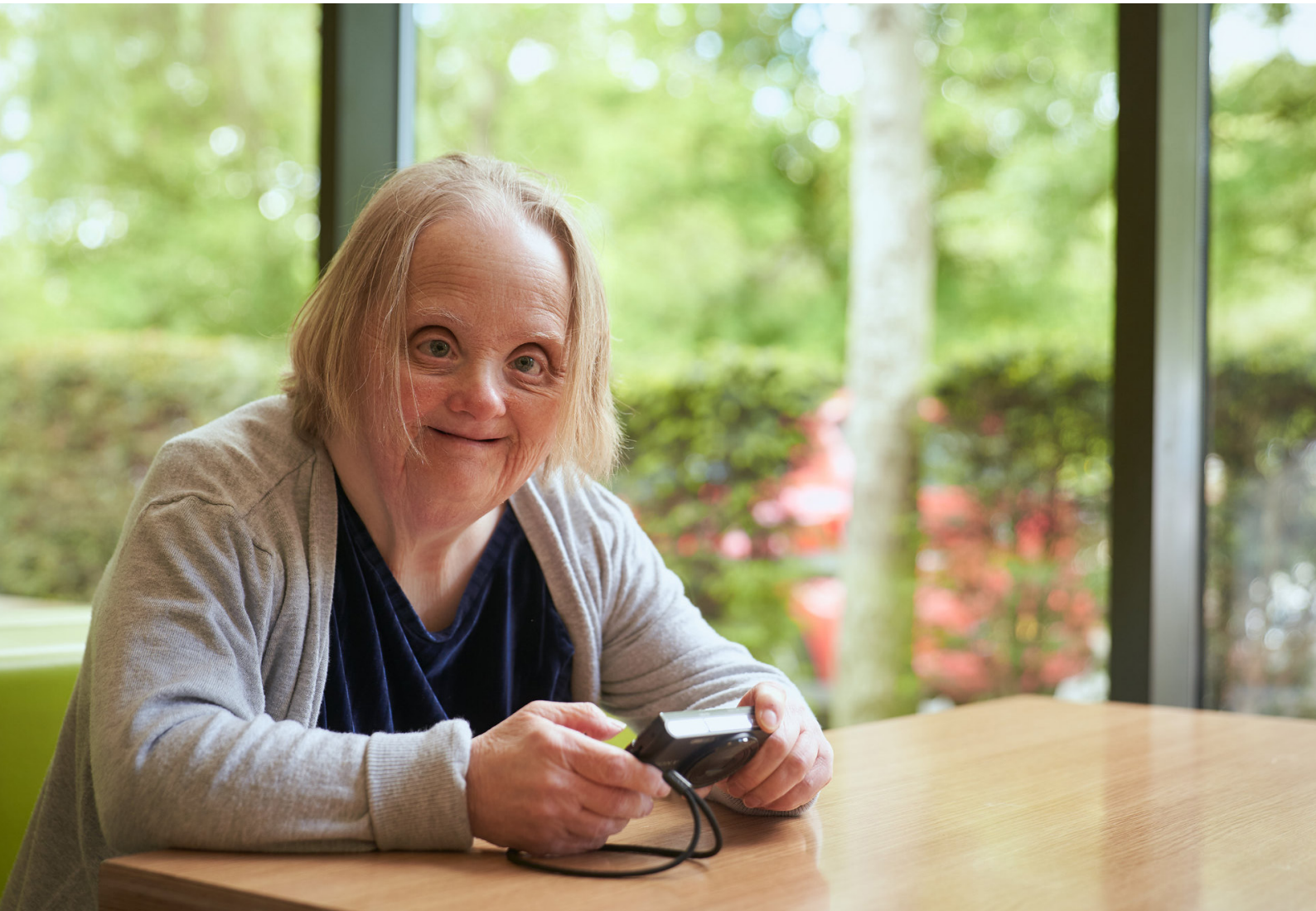
It is not immediately obvious to MPs that some of their constituents are bound up in this (though often will be living Out Of Area), nor that they have ATUs in their constituency. We should help match ATUs to their constituency MPs so that MPs can monitor and encourage progress at a local level.

4 What you can do to help

Please write to your constituency MP and ask them to join this APPG.
A template letter is available.

Write to us and lend you and your organisation's support to the policies:
marketing@dimensions-uk.org.

The more organisations that support these policies, the louder our voice will be.



Proving life can get better

Dimensions provides evidence-based outcomes-focussed support for people with learning disabilities, autism and complect needs. We help people to be actively engaged in their communities.

Find out more us

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