Who Chooses Where You Live?

A snapshot of Adult Social Care Choice Policies, and a few ideas

Fleur Perry, 2019

Background

On 29th March 2019, an article was published by John Pring on Disability News Service that detailed concerns over the actions of Barnet Council (Pring, 2019):

"Tory council set to force disabled people into residential care to cut costs

"Barnet council wants to save more than £400,000 in 2019-20 by creating more "cost effective support plans", such as using residential care rather than funding support packages that allow disabled people to live in their own homes.

"The north London council says it wants to consider "the full range of care options to meet eligible needs (eg residential care), rather than offering community-based placements (eg supported living) by default".

"This means a new "assumption that new clients are placed in cheaper accommodation settings where appropriate"."

Residential accommodation by default is a threat to the Independent Living movement and to disabled peoples' choice and control over their own lives.

It can also be framed as a human rights issue. Under the Human Rights Act, everyone has a right to have their Private & Family Life respected (Article 8) (EHRC, 2018). If this right is interfered with in a way that is not justifiable, then a decision that overrides a person's choice could be unlawful. Competing interests and consequences need to be carefully weighed up. It's not enough to simply say "We're going to do this because money", as every situation is different, though we all have the same rights.

Examining NHS Continuing Healthcare policies two years ago (Perry, 2017), it became apparent that to determine if a decision is proportional, the alternatives must be fully considered. If someone is being moved to residential/nursing accommodation despite a preference to stay in their own home, the costs of care and support services needed for them to remain in their own home must be calculated and documented. The following research was carried out under the assumption that the same legal principles may apply to decisions made by councils when carrying out their duties under the Care Act to meet a person's Adult Social Care Needs.

This report seeks to answer the question: If one council is acting in this way, are there others?

... and to explore the questions: Are people's choices being respected? Are they being arbitrarily restricted? What could be done differently?

Note: I am not a lawyer, nor an academic, just a very nosey Independent Living enthusiast. All errors are my own.

Thanks to the Disability Horizons team and Belinda Schwehr for their support.

Methodology

Original FOI sent on 3/6/2019 to every council with responsibility for Adult Social Care:

"Please could you send all current policy documents relating to Adult Social Care and choice over in which setting care is to be provided to a person."

Clarification provided on request:

"I am seeking all policies, guidance, or other documents which detail how the decision is to be made over whether someone receives care in their own home or is to move to a residential/nursing home facility."

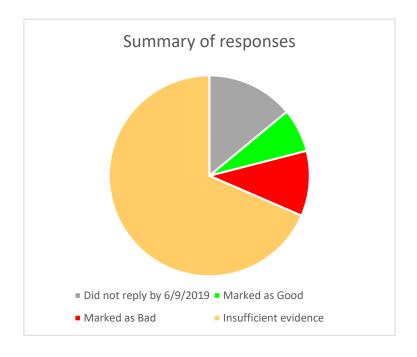
Those who had not replied by 3/7/2019 were phoned or emailed as the initial response deadline had been missed.

The responses were read carefully, noting any points that would indicate how the local authority would make a decision about where a person with capacity will live whilst receiving the care and support they need. Where laws and guidance were quoted, these were also read and notes made.

Results

As of 6/9/2019, full replies had been received from 172 local authorities with responsibility for Adult Social Care (out of a total of 200 FOI requests sent).

The majority sent information already available to the public on how to request an assessment for Adult Social Care, stated they followed current guidance, or sent more detailed information which did not clarify their approach. These responses have been marked with a tilde "~" in the database, as the responses contained no evidence that they are arbitrarily placing people into residential/nursing accommodation against their choice, but also no evidence that they strongly oppose this practice.



The good

There are 14 responses that appear to actively promote Independent Living and choice over and above legal requirements, or take a proportional approach thus respecting a person's Human Rights. These can be found in the database marked with a "Y".

- Bury Metropolitan Borough Council
- Cheshire East Council
- Falkirk District Council
- Gwynedd Council
- Hampshire County Council
- Isle of Anglesey Council
- Kirklees Metropolitan Borough Council
- London Borough of Hackney
- London Borough of Lewisham
- Monmouthshire Council
- Nottinghamshire County Council
- Sheffield City Council
- Tameside Metropolitan Borough Council
- Trafford Council

Please note that policy and practice may differ; this list is purely drawn from the quality of the local authority responses.

Here are a few highlights:

Isle of Anglesey County Council: "Care provision is based on individual choice and needs and it is not for the Local Authority to dictate where care is best provided."

Monmouthshire Council: "Our priority is to support someone to stay at home."

Trafford Council: "In terms of 'choice', a person would only have the ability to access available resources at any given time. When we refer to resources, we do not automatically differentiate between types of support or specify setting, this can vary as to what someone wants or needs. Therefore, a policy document which prescribes choice within a varied and often competitive care market, that can also comprise tailored and creative solutions cannot readily or robustly be relied upon."

The bad

There are 22 responses that appear to actively oppose Independent Living, arbitrarily restrict choice, or take an approach which is not proportional. These can be found in the database marked with a "N".

- Aberdeen City Council
- Bedford Borough Council
- Bournemouth, Christchurch and Poole Council
- Calderdale Council
- Dorset Council
- Herefordshire Council
- Lancashire County Council
- London Borough of Brent
- London Borough of Camden
- London Borough of Haringey
- London Borough of Richmond upon Thames
- Merthyr Tydfil Council
- Milton Keynes Council
- Newport Council
- Orkney Islands Council
- Rutland County Council
- Solihull Metropolitan Borough Council
- Wakefield City Metropolitan District Council
- West Berkshire Council
- West Sussex County Council
- Wiltshire Council
- Worcestershire County Council

Please note that policy and practice may differ; this list is purely drawn from the quality of the local authority responses.

Here are a few highlights:

Bedford Borough Council: "The maximum weekly cost to Bedford Borough Council will be no more than the net weekly cost to Bedford Borough Council of a care home placement that could be commissioned to meet the individual's assessed eligible needs."

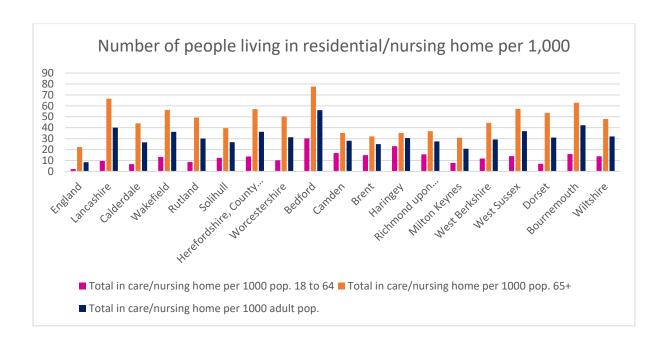
Milton Keynes Council: "if the adult's preference differs from that recommended by the worker, and both meet the adult's assessed needs, then the duty to achieve best value for the Council would normally prevail."

Wiltshire Council: "If an adult chooses to stay at home in instances when the value of an individual adult's personal budget will significantly exceed the value of support in a care home, the Council will offer the adult the equivalent value minus any funded nursing care and 'hotel costs' so that they can fund care packages at home."

Impact of these policies

Local authority expenditure on Adult Social Care is captured in the dataset Adult Social Care Activity and Finance Report, England - 2017-18 [PAS] (NHS Digital, 2018). When the numbers of people living in residential/nursing accommodation and 2011 Census data are used, we can compare rates per 1000 population.

Of those local authorities in England who have policies that could be considered concerning, all have much higher rates of people living in residential/nursing accommodation than the national average.



Themes

Hospital discharges

Some responses cited local hospital discharge policies. Some of these appeared to completely remove choice from the hospital discharge process, for example:

Pan-Dorset Policy for Managing Choice on Hospital Discharge: "3.3 If there is currently at least one available option, the patient cannot remain in hospital to wait for further choices and must accept one that is available, at least on a temporary basis."

Residential and Nursing Placements Policy: "When considering long term accommodation placements, Brent Council will use the criteria set out below in finding a placement at a care home and presenting the individual and their family with the option/s:

- The placement must meet the person's needs
- The home must have an available bed
- If care homes in the borough do not have an available placement, we will look for homes outside of Brent
- The cost of the placement is reasonable based on our usual rates (see section below on usual rates for definition)
- Where there are no placements available at or below our usual rates, the council will seek to find the most reasonable option/s available above our usual rates...

London Borough of Brent, Residential and Nursing Placements Policy: "Disputes

Disputes over placements should not result in extended hospital admissions. If a patient's advocate is not willing to accept a placement following a reasonable offer from the options available, then they may be placed in an interim placement, where there will be no choice of home or location. We will also ask the hospital involved to implement their own eviction policy.

While the council will seek to be flexible where possible when making residential or nursing placements, at the time the hospital declares an individual to be medically fit for discharge, there will be a maximum of 24 hours before a final decision will be made and the individual and family has either agreed a placement, is placed in an interim placement or referred to the hospital's eviction policy."

This could be argued to be fettered discretion, and thus may be unlawful.

The transferring of responsibilities from an NHS hospital to the local authority must also be carefully handled. Each has responsibilities to the individual, and to set fixed expectations may compromise the ability for each organisation to fulfil their duties.

Recommendation: NHS Hospital discharge policies to avoid completely eliminating choice by mandating that a person must move on a specified date if a place is available at the only care home on a list of one provided by the local authority.

Personal budgets suitable for a single option

Some responses discussed how a personal budget would offer the opportunity for choice and control. However, in some responses, the personal budget was to be set to an amount that would fund only one setting. This also acts to remove choice. For example:

London Borough of Richmond upon Thames, DASS Personalisation and Choice Policy: "The Act requires local Councils to ensure that the person has a genuine choice of accommodation. This means ensuring that at least one accommodation option is available and affordable within the person's personal budget. This right applies as long as the person's assessed eligible needs and the outcomes they have identified during the planning process can be met in the chosen setting and cost of the chosen provider or setting is not more than the personal budget or more than the Council would pay for this service from another provider for example."

Others actively oppose this practice:

Southampton City Council, Adult Social Care and Support Planning Policy: "3.3. The Council will take decisions on a case-by-case basis that weigh up the total cost of different potential options for meeting needs, and include the cost as a relevant factor in deciding between suitable alternative options for meeting needs. This does not mean choosing the cheapest option; but the one that delivers the outcomes desired for the best value. The Council will impose no arbitrary ceiling on the value of personal budgets, nor will personal budgets be reduced in order to meet a defined level of expenditure."

Recommendation: Adult Social Care Choice policies to avoid completely eliminating choice by setting a personal budget that allows a person to choose from a list of one. Multiple options to be available from which to choose, with any restrictions justified.

Passive language

Although passive language does not mean that the individual's right to choice has been removed, it could be argued that it feels like a person is being spoken about like a box, without any say on where it's going. For example:

Somerset County Council: "As it stands, we can confirm that an adult is placed in a setting according to their assessed needs and this could be residential, special residential or nursing."

Others make it clear that both professionals and people receiving Adult Social Care have an active role in the process of assessing needs and arranging care and support. For example:

Norfolk County Council: "The service user's choice should be respected in relation to placement. However, guidance may be required by the practitioner as to suitability and availability. Practitioners should provide relevant signposting and information to maximise choice."

Recommendation: Policy writers use language that recognises the roles and rights of all parties involved at every stage.

Other recommendations from reading through the responses

It may be that some of those with concerning policies are not so bad in practice, and that a small error in the language makes it seem like choice is being restricted. In others, the local authority's intention seems very clear.

Recommendations:

- Caps, maximums, set expectations or similar ways of limiting choice on grounds of predetermined expenditure are not used.
- The option for a person to stay in their own home is not excluded as a matter of policy.
- Automatic selection of the cheapest option without consideration of a person's choice is not included in a policy.
- People's rights are fully respected beyond merely being supported to "express a preference"; that choice must be given due weight.
- Any multi-disciplinary meetings to include not just the family, but also the person, unless they choose otherwise.
- The choice is given to the person, not their family unless the person consents to someone else making that choice.
- People are advised of their legal rights and where to find legal advice in the event of a dispute.
- No accommodation types that meet assessed need are excluded from the choice-making process without justification.
- When setting banding arrangements which fix prices, local authorities to seek and follow advice from the Competition and Markets Authority to prevent acting in a way which may inhibit competition.

Some of the above is already mandated by law, however on reading the policies, it seemed reminders were needed.

Law

Many responses cited legislation.

Care Act 2014, Cases where adult expresses preference for particular accommodation (Legislation.gov, 2014)

- (1) Regulations may provide that where—
- (a) a local authority is going to meet needs under sections 18 to 20 by providing or arranging for the provision of accommodation of a specified type,
- (b) the adult for whom the accommodation is going to be provided expresses a preference for particular accommodation of that type, and
- (c) specified conditions are met, the local authority must provide or arrange for the provision of the preferred accommodation.
- (2) The regulations may provide for the adult or a person of a specified description to pay for some or all of the additional cost in specified cases or circumstances.
- (3) "Additional cost" means the cost of providing or arranging for the provision of the preferred accommodation less that part of the amount specified in the personal budget for the purposes of section 26(1)(a) that relates to the provision of accommodation of that type.

There is no description here of how a personal budget amount is to be set in order to determine how much cost is "additional".

Recommendation: Clarity needed.

The Care and Support and After-care (Choice of Accommodation) Regulations 2014, Choice of accommodation (Legislation.gov, 2014)

- 2.-(1) Where-
- (a) a local authority(<u>5</u>) is going to meet needs under sections 18 to 20 of the [Care] Act by providing or arranging for the provision of accommodation of a specified type in England;
- (b) the adult(<u>6</u>) for whom the accommodation is to be provided expresses a preference for particular accommodation (identifiable by reference to its address or provider) of a specified type; and
- (c) the conditions in regulation 3 are met,

the local authority must provide or arrange for the provision of the preferred accommodation in accordance with these Regulations.

- (2) The specified types of accommodation are—
- (a) care home accommodation (see regulation 6);
- (b) shared lives scheme accommodation (see regulation 7); or
- (c) supported living accommodation (see regulation 8).

Conditions for provision of preferred accommodation

- **3.**—(1) The following conditions must be met for the provision of preferred accommodation under regulation 2—
- (a) the care and support plan(7) for the adult specifies that the adult's needs are going to be met by the provision of accommodation of a specified type;

- (b) the preferred accommodation is of the same type as that specified in the adult's care and support plan;
- (c) the preferred accommodation is suitable to the adult's needs;
- (d) the preferred accommodation is available; and
- (e) where the preferred accommodation is not provided by the local authority, the provider of the accommodation agrees to provide the accommodation to the adult on the local authority's terms.
- (2) If the cost to the local authority of providing or arranging for the provision of the preferred accommodation is greater than the amount specified in the adult's personal budget($\underline{\mathbf{8}}$) that relates to the provision of accommodation of that type, the additional cost condition in regulation 5 must also be met($\underline{\mathbf{9}}$).

There is only the option given here to specify one type of accommodation. It may be that a person's needs may be met by more than one setting type, and that this may allow the person wider choice.

Recommendation: No accommodation types that meet assessed need are excluded from the choice-making process without justification.

This does not take into account that many local authorities hold a stock of social housing, and that there is nothing to prevent them from building or purchasing suitable accommodation that would better meet a person's needs long term.

Recommendation: Two further options are added.

(d) permanent or temporary accommodation arranged by the local authority separately to care and support services either through Adult Social Care budget or local social housing provision (e) other suitable option, for example a housing co-operative.

The Care and Support (Eligibility Criteria) Regulations 2015 (Legislation.gov, 2015)

Needs which meet the eligibility criteria: adults who need care and support

- 2.—(1) An adult's needs meet the eligibility criteria if—
- (a) the adult's needs arise from or are related to a physical or mental impairment or illness;
- (b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes specified in paragraph (2); and
- (c) as a consequence there is, or is likely to be, a significant impact on the adult's well-being.
- (2) The specified outcomes are—
- (a) managing and maintaining nutrition;
- (b) maintaining personal hygiene;
- (c) managing toilet needs;
- (d) being appropriately clothed;
- (e) being able to make use of the adult's home safely;
- (f) maintaining a habitable home environment;
- (g) developing and maintaining family or other personal relationships;
- (h) accessing and engaging in work, training, education or volunteering;
- (i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and

- (j) carrying out any caring responsibilities the adult has for a child.
- (3) For the purposes of this regulation an adult is to be regarded as being unable to achieve an outcome if the adult—
- (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.

National eligibility criteria were mentioned in several responses, however none directly cited these regulations.

Though this doesn't explicitly talk about choice of accommodation, there is a wider point to note. It specifies that an eligible person must be unable to achieve two or more outcomes. This means that a person may be unable, or unable safely or painlessly, to do one of the listed outcomes and yet not be eligible for support. These outcomes are recognised to have "a significant impact on the adult's well-being", and yet there is no statutory duty to support a single outcome, though within the Care Act 2014 local authorities may provide this support if they choose to do so.

This could be considered a human rights concern:

ARTICLE 3, Prohibition of torture

"No one shall be subjected to torture or to inhuman or degrading treatment or punishment." (European Court of Human Rights, 2010)

If being refused care and support to achieve one of these outcomes, even in the absence of other needs, significantly impacted a person's wellbeing, it seems likely there could be a point at which it could be considered degrading treatment.

Recommendation: Eligibility criteria to be changed. All care and support needs are met, even if only one listed outcome is impacted.

Ten outcomes are listed, but do they cover the full range of outcomes which may have a significant impact on a person's wellbeing? For example, the dataset "Health Survey for England 2016: Social care for older adults" (NHS Digital, 2016) notes that whilst 8% of adults over 65 "needed help" taking medicine, only 5% "received help". This means that 3% of adults over 65 did not receive support needed with medication, which seems likely to have a significant detrimental impact on their health and thus their wellbeing. This need would usually be met by Adult Social Care if the person did not have the level of health needs to meet the eligibility criteria for NHS Continuing Healthcare. Despite this, taking medication is not listed as an outcome in the above eligibility criteria.

Recommendation: The eligibility criteria are extended, perhaps like this:

- "(k) taking medication;
- (I) any other documentable outcome which meets (1)(c)

Gloucestershire County Council responded: "Best value

The County Council has to discharge its duties to provide services within the 'best value' requirements of the Local Government Act 1999. The cost of accommodating a resident should not require the County Council to pay more than it would usually expect to pay for someone with similar assessed needs. Please refer also to the County Council's Best Value policy."

From Gloucestershire County Council's website (gloucershire.gov.uk, 2019): "The Adult Social Care Best Value policy is currently under review"

Local Government Act 1999 (Legislation.gov, 1999)

3 The general duty.

- (1) A best value authority must make arrangements to secure continuous improvement in the way in which its functions are exercised, having regard to a combination of economy, efficiency and effectiveness.
- (2) For the purpose of deciding how to fulfil the duty arising under subsection (1) an authority must consult—
- (a) representatives of persons liable to pay any tax, precept or levy to or in respect of the authority,
- (b) representatives of persons liable to pay non-domestic rates in respect of any area within which the authority carries out functions,
- (c) representatives of persons who use or are likely to use services provided by the authority, and
- (d) representatives of persons appearing to the authority to have an interest in any area within which the authority carries out functions.

There is nothing apparent in the Local Government Act 1999 that demands that a set amount must be paid for a specified service or type of service.

Social Services and Well-being (Wales) Act 2014 (Legislation.gov, 2014)

Cases where a person expresses preference for particular accommodation

- (1) Regulations may provide that where—
- (a) a local authority is going to meet needs under sections 35 to 38 or sections 40 to 45 by providing or arranging for the provision of accommodation of a specified type for a person,
- (b) the person concerned, or a person of a specified description, expresses a preference for particular accommodation of that type, and
- (c) specified conditions are met, the local authority must provide or arrange for the provision of the preferred accommodation.
- (2) The regulations may require the person concerned or a person of a specified description to pay some or all of the additional cost (if any) of the preferred accommodation in specified cases or circumstances.
- (3) In subsection (2) "additional cost" means the difference between—
- (a) the cost of providing or arranging the provision of the preferred accommodation, and
- (b) the cost that the local authority would usually expect to incur in providing or arranging the provision of suitable accommodation of that type to meet the needs of the person concerned.

There is only the option given here to specify one type of accommodation. It may be that a person's needs may be met by more than one setting type, and that this may allow the person wider choice.

Recommendation: No accommodation types that meet assessed need are excluded from the choice-making process without justification.

The phrase "the cost that the local authority would usually expect to incur" could be interpreted as cost-capping. There appears to be no room for exceptional circumstances.

If only one setting is available for the price the local authority would "usually expect" to pay and the person is unable pay the "additional cost", then this could act to completely remove choice.

Recommendation: Clarity needed.

The Care and Support (Choice of Accommodation) (Wales) Regulations 2015 (Legislation.gov, 2015)

Choice of accommodation

- 2. Where-
- (a) a local authority (5) is going to meet needs under sections 35 to 38 of the Act by providing or arranging for the provision of care home accommodation in the United Kingdom;
- (b) the person for whom the accommodation is to be provided expresses a preference for a particular care home; and
- (c) the conditions in regulation 3 are met,

the local authority must provide or arrange for the provision of the preferred accommodation in accordance with these Regulations.

Conditions for provision of preferred accommodation

- 3.—(1) The following conditions must be met for the provision of preferred accommodation under regulation 2—
- (a) the care and support plan for the person specifies that the person's needs can be met by the provision of care home accommodation;
- (b) the preferred accommodation is suitable to the person's needs;
- (c) the preferred accommodation is available; and
- (d) where the preferred accommodation is not provided by the local authority, the provider of the accommodation agrees to provide the accommodation to the person on the local authority's terms.
- (2) If the cost to the local authority of providing or arranging for the provision of the preferred accommodation is greater than the cost that the local authority would usually expect to incur in providing or arranging the provision of care home accommodation to meet the needs of the person concerned, the additional cost condition in regulation 4 must also be met(6).

The phrase "the cost that the local authority would usually expect to incur" could be interpreted as cost-capping. There appears to be no room for exceptional circumstances.

If only one setting is available for the price the local authority would "usually expect" to pay and the person is unable pay the "additional cost", then this could act to completely remove choice.

Recommendation: Clarity needed.

Scottish Borders Council responded: "The Social Work (Scotland) Act 1968 (Choice of Accommodation) Directions 19934 apply to local authorities that arrange care home accommodation to a person under the Social Work (Scotland) Act 1968 (the 1968 Act). The directions place a duty on local authorities in Scotland to arrange places for people in a care home of their choice, provided:

- The accommodation is suitable in relation to the individual's assessed needs.
- To do so would not cost the authority more than it would usually expect to pay for accommodation for someone with the individual's assessed needs.
- The accommodation will be available within a reasonable period
- The person in charge of the accommodation is willing to provide accommodation, subject to the authority's usual terms and conditions for such accommodation."

There is no room for exceptionality - if a person's needs are similar to others but there are differing circumstances that had led them to choose accommodation at a higher cost.

Recommendation: Room is made for exceptions to what a local authority may "usually expect" and clarification needed.

Fife Council cites: Social Care (Self-directed Support) (Scotland) Act 2013 (Legislation.gov, 2013)

- 1 General principles
- (1) A local authority must have regard to the principles in subsections (2) to (4) in carrying out its functions under—
- (a) Part 2 of the 1968 Act (other than the provisions mentioned in subsection (5)),
- (b)sections 22 to 24 of the 1995 Act,
- (c) this Act.
- (2) A person must have as much involvement as the person wishes in relation to—
- (a) the assessment of the person's needs for support or services, and
- (b) the provision of support or services for the person.
- (3) A person must be provided with any assistance that is reasonably required to enable the person—
- (a) to express any views the person may have about the options for self-directed support, and
- (b) to make an informed choice when choosing an option for self-directed support.
- (4) A local authority must collaborate with a person in relation to—
- (a) the assessment of the person's needs for support or services, and
- (b) the provision of support or services for the person.

...

2 Further general principles applicable to this Act In carrying out its functions under this Act in relation to a person who is to choose (or has chosen) one of the options for self-directed support, a local authority must take reasonable steps to facilitate the following general principles—

- (a) that the right to dignity of the person is to be respected,
- (b) that the person's right to participate in the life of the community in which the person lives is to be respected.

Though a person has a right to make a choice over which self-directed support option they would like to take, this is a choice over how financial arrangements are managed, not over accommodation.

A person must have an involvement over how they are to be supported, but this does not equate to a choice of accommodation.

Recommendation: Addition of words to the effect of "Where a support plan requires a local authority to provide accommodation, the person must be able to make a meaningful choice."

Guidance

Cheshire East Council cites "Care and Support Statutory Guidance (updated Oct 2018) and in particular Annex A: Choice of accommodation and additional payments" (Department of Health & Social Care, 2018)

"Choice of accommodation

8.36 Where the care planning process has determined that a person's needs are best met in a care home, the local authority must provide for the person's preferred choice of accommodation, subject to certain conditions. This also extends to shared lives, supported living and extra care housing settings. Determining the appropriate type of accommodation should be made with the adult as part of the care and support planning process, therefore this choice only applies between providers of the same type.

8.37 The local authority must ensure that the person has a genuine choice of accommodation. It must ensure that at least one accommodation option is available and affordable within the person's personal budget and it should ensure that there is more than one of those options. However, a person must also be able to choose alternative options, including a more expensive setting, where a third party or in certain circumstances the resident is willing and able to pay the additional cost ('top-up'). However, an additional payment must always be optional and never as a result of commissioning failures leading to a lack of choice. Detailed guidance is set out in Annex A which a local authority must have regard to."

There is only the option given here for a person to make a choice from the options made available by the local authority within one specified type of accommodation. It may be that a person's needs may be met by more than one setting type, and that removing this restriction may allow the person wider choice.

Recommendation: No accommodation types that meet assessed need are excluded from the choice-making process without justification.

One accommodation option available does not ensure "genuine choice" of accommodation. If a person's needs cannot be met in their current accommodation, if a personal budget were to be set to an amount that would fund only one setting, the person would have to remain in a potentially unsafe situation, or move to the only option available that would meet their needs within the personal budget. Worse still, if a person's current accommodation were to become unviable (care home closure, hospital discharge, eviction notice from landlord, flooding and other major damage), and the personal budget were to be set to an amount that would fund only one setting, the person would be faced with a choice between moving to the only option available that would meet their needs within the personal budget, or homelessness. This effectively removes choice.

Recommendation: Multiple options to be available within a personal budget to ensure "genuine choice".

Fife Council: "We act in accordance with the Social Care (Self-directed Support) (Scotland) Act 2014 which is informed by the national guidance..." (Scottish Government, 2014)

"Residential Care

14.25 Residential Care is a social care service. Assessments which result in a decision to receive care and support in a group setting are social care assessments. As such the authority should undertake any assessment which may result in residential care in line with this guidance. For example, the general principles of assessment set out in Section 1 of the 2013 Act apply in exactly the same way as any other context. The authority must collaborate with the supported person, ensure that the person can make informed choices and involve the supported person in their assessment. The provision of alternative options can provide the supported person with an opportunity to choose an option other than residential care support."

This encourages choice but could be clearer and stronger.

Recommendation: Addition of "The authority must consider all options, including independent living, and make sure the person has a meaningful choice, not only between settings of the same type, but between settings of all suitable types."

West Sussex Council have a unique tool: AS275 Human Rights Act Assessment:

"Will any action being proposed give rise to a breach of human rights? Yes/No"

"Article 8 - Will there be an interference with the right to private and family life, home and correspondence?

Record all relevant information including:

Does the person have family members or very close friends?

Are those relationships likely to be affected by the proposed action? If so, explain how those relationships would be affected.

Is there any other person whose rights are likely to be affected by the proposed action, such as a friend or family member?

What impact, if any, will there be on the person's psychological wellbeing or personal identity? How significant is the impact likely to be?

Could the proposed action affect the person's right to a private life? If so, provide details.

Could the proposed action affect the person's right to a family life? If so, provide details.

Could the proposed action affect the person's right to a home and correspondence? If so, provide details.

How significant is the impact likely to be?"

This doesn't consider the person's opportunities to form future family relationships and friendships.

Recommendation: Future opportunities to be considered.

Summary of recommendations

NHS Hospital discharge policies to avoid completely eliminating choice by mandating that a person must move on a specified date if a place is available at the only care home on a list of one provided by the local authority.

Adult Social Care Choice policies to avoid completely eliminating choice by setting a personal budget that allows a person to choose from a list of one. Multiple options to be available from which to choose, with any restrictions justified.

Policy writers use language that recognises the roles and rights of all parties involved at every stage.

Other recommendations on local Choice policies:

- Caps, maximums, set expectations or similar ways of limiting choice on grounds of pre-determined expenditure are not used.
- The option for a person to stay in their own home is not excluded as a matter of policy.
- Automatic selection of the cheapest option without consideration of a person's choice is not included in a policy.
- People's rights are fully respected beyond merely being supported to "express a preference"; that choice must be given due weight.
- Any multi-disciplinary meetings to include not just the family, but also the person, unless they choose otherwise.
- The choice is given to the person, not their family unless the person consents to someone else making that choice.
- People are advised of their legal rights and where to find legal advice in the event of a dispute.
- No accommodation types that meet assessed need are excluded from the choice-making process without justification.
- When setting banding arrangements which fix prices, local authorities to seek and follow advice from the Competition and Markets Authority to prevent acting in a way which may inhibit competition.

Clarity needed in the Care Act 2014 as to how a personal budget amount is to be set in order to determine how much cost is "additional".

The Care and Support and After-care (Choice of Accommodation) Regulations 2014, to be amended such that no accommodation types that meet assessed need are excluded from the choice-making process without justification.

Two further options are added to the specified types of accommodation within The Care and Support and After-care (Choice of Accommodation) Regulations 2014:

- (d) permanent or temporary accommodation arranged either through Adult Social Care budget or local social housing provision
- (e) other suitable option, for example a housing co-operative.

The Care and Support (Eligibility Criteria) Regulations 2014 to ensure all care and support needs are met, even if only one listed outcome is impacted.

The Care and Support (Eligibility Criteria) Regulations 2014 to extend the eligibility criteria, perhaps like this:

- "(k) taking medication;
- (I) any other documentable outcome which meets (1)(c)

Social Services and Well-being (Wales) Act 2014 to be amended such that no accommodation types which meet assessed need are excluded from the choice-making process without justification.

Social Services and Well-being (Wales) Act 2014 to clarify "usually expect to incur" and "additional cost" in a way that does not act to restrict choice.

The Care and Support (Choice of Accommodation) (Wales) Regulations 2015 to clarify "usually expect to incur" and "additional cost" in a way that does not act to restrict choice.

The Social Work (Scotland) Act 1968 (Choice of Accommodation) Directions make room for exceptions to what a local authority may "usually expect" and clarify what is meant.

Social Care (Self-directed Support) (Scotland) Act 2013 to add words to the effect of "Where a support plan requires a local authority to provide accommodation, the person must be able to make a meaningful choice."

Care and Support Statutory Guidance to be amended such that no accommodation types that meet assessed need are excluded from the choice-making process without justification.

Care and Support Statutory Guidance to be amended such that multiple options are to be available within a personal budget to ensure genuine choice.

Social Care (Self-directed Support) (Scotland) Act 2013 to add words to the effect of "Where a support plan requires a local authority to provide accommodation, the person must be able to make a meaningful choice."

Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013 to add words to the effect of "The authority must consider all options, including independent living, and make sure the person has a meaningful choice, not only between settings of the same type, but between settings of all suitable types."

West Sussex Human Rights Act Assessment to be amended such that future opportunities are to be considered.

Concluding remarks

Where you choose to live and who you choose to live with is a key decision that will shape every other aspect of your life. To have this removed, seemingly arbitrarily, is an experience no one would wish for themselves or others.

For non-disabled people, to have this choice removed would be out of the question. For some disabled people with care and support needs, the reality is that the act of making a choice has to be justified and fought for, and the removal of that choice is not subject to the same level of scrutiny. The burden of evidence can fall on the individual, and not the local authority.

The legal framework and guidance used at present does not protect a person's right to Independent Living. Though "genuine choice" is emphasised as a key principle, restrictions that seem to completely remove or limit choice without justification are not difficult to find.

Rates of reliance on the care/nursing home sector as a solution for providing for a person's needs vary widely across the country. Deinstitutionalisation can be statistically monitored. This can make identifying areas of good practice easier and learnings can be shared.

In the long term, if changes are made, we would expect the numbers of people living in care/nursing homes to slowly decrease as other options are made more available.

Not all local authorities appear to be acting within the current legal framework, and some appear to be actively undermining choice. Financial pressure and the need to fairly distribute resources seems to be a driver in some policies, but how this is balanced with impacts on a person's wellbeing and freedom to live in the place and manner of their choosing varies greatly from area to area. To ignore the legal framework for financial reasons with the result that people may be moved against their choice without clear justification is a dangerous position for a local authority to put itself in.

For those who wish to take this further, **there may be the option of Judicial Review**, either by an overseeing body, or someone who feels their rights have been ignored.

There is a wider debate on social care to be considered, and your responses would be of great interest. Please tweet your answers to @perry_fleur:

Q: What standard of living would you want for yourself if you were to need social care in the future? A:

Q: To what extent are the restrictions on choice of where and how to live fair and necessary? $\Delta \cdot$

Q: Would the policy makers themselves be satisfied in a situation where they were subject to their own policy?

A:

Q: How can we do better?

A:

I believe we can do better.

Institutionalisation by default - apart from being unlawful - is the most restrictive policy option available.

What if we considered the least restrictive option? If we did all we could to ensure that people with social care needs have as much choice as possible? If that level of choice were to be made as similar as possible to the level of choice available to those without social care needs? Would this deliver a standard of living that policy makers would accept for themselves?

Perhaps. Whatever your vision, change is needed.

Changes must be made to ensure that people can meaningfully make choices about their own lives without undue pressure or restriction.

We can make change happen, and have already made a commitment to do so. The UK is a signatory to the United Nations Convention on the Rights of Persons with Disabilities, including:

"Article 19 – Living independently and being included in the community States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community..."

As yet, these commitments have not been written into our legislation.

Given the evidence found here, I would not only support Article 19 being written into law, but join the growing calls for the creation of an Independent Living Act.

Local and national policy makers need to engage with disabled people and DDPOs (Deaf and Disabled People's Organisations) to make change happen.

In addition to a legal right to Independent Living, suitable mechanisms must be in place to defend these rights, including:

- readily available and accessible information on what those rights are;
- accessible information on how to access legal support and legal aid;
- the ability for representative groups (including DDPOs) to challenge a policy before someone's rights are breached, as opposed to only being able to support an individual who may have already experience harm.

Thank you for reading.

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