

Housing Choices

Discussion Paper 4: Policy and Practice Recommendations

Paper 4 of 4 in the Housing Choices Discussion Series:

Exploring and comparing the characteristics of housing and support arrangements for people with care and support needs

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Introduction

The National Development Team for Inclusion (NDTi) has a vision of a society where all people, regardless of age or disability, are valued and able to live the life they choose.

NDTi have published three papers in this series on housing and support for disabled people and older people who are in need of support:

Paper 1 scoped the existing evidence of the cost effectiveness of different models of housing and support. In summary, this showed that beyond the long recognised poorer outcomes from large institutions, there is no robust evidence to demonstrate that any one housing and support model is more cost effective than others. Our conclusion from this is that commissioners (and indeed providers) cannot justify taking decisions between different models on price alone - other than going for the cheapest option without considering outcomes for people. Commissioners also need to explicitly consider the extent to which different approaches promote and sustain rights, choice and community inclusion (around which there is also only limited evidence).

Paper 2 proposed a typology for housing and support options. Given what is essentially a simplistic use of terms such as supported living or residential care without understanding what lies behind such phrases, the typology identified eight different main categories housing and 21 sub-categories. These are differentiated in important ways by a range of structural, legal and support factors that have implications for the lifestyles of the people who will live in them.

Paper 3 took that typology and explored the extent to which each typology or model promotes (through its legal or structural make-up) people's rights, choice and personal control over how they live their lives, have their support provided, and the potential for inclusion in their community. This demonstrated significant differences between different models (in theory).

This fourth and final paper seeks to draw policy and practice recommendations from the discussion and debate around the previous papers. We would like to thank all those who have contributed to this – both on-line and through direct contact with us.

There are two points to clarify prior to describing our recommendations.

Firstly, whilst these papers are about housing AND support, they start from looking at the housing arrangements and then build support options onto that. The actual place (housing) where people live and their ability to control and determine that living situation is a core

cultural element of British society. People's physical home is important to them. These papers have therefore been concerned with how that cultural requirement is experienced by disabled and older people who also need support in their daily lives – whether that housing and support is bound together in a structural/contractual way or not.

In terms of how support is then provided, we are conscious that different support providers operating within essentially the same housing model will do things very differently. This is addressed in part in the recommendation below about promoting best practice. However, our starting point is to recommend changes that will address or remove the potential within any legal or policy framework that allows for people's rights, choice, control and community inclusion to be ignored or marginalised by poor practice that is still within the law or policy.



Discussion Paper 4: Policy and Practice Recommendations

Recommendation 1. Addressing the lack of evidence to inform effective commissioning.

As Paper 1 showed, there is insufficient evidence to show which types of housing and support are most cost effective i.e. the outcomes achieved with and for people compared to the amount of money spent¹. There is some evidence that, for people with mental health problems, individual or shared supported housing options are lower cost than residential care and for people with learning disabilities whose behaviour is described as challenging, some evidence that small scale individualised services provide better outcomes at a lower cost. Beyond that however, there is little that can be said with confidence and certainly little comparative evidence in relation to older people.

Overall, there is some evidence that it is cheaper to buy large-scale residential care – but the effect of that on people’s life outcomes is largely unknown. Thus the wisdom of spending money on such services has to be questioned given the related evidence on negative outcomes from institutional services and the potential impact described in our typology on rights, choice, control and community inclusion.

Considering the amount of public (and self-funder) money spent on housing and support², this lack of evidence on cost effectiveness is quite astounding. We recommend that Governments (across the UK), Research Councils and representative bodies of both commissioners and providers should invest in a substantial programme of inclusive research that rapidly seeks to plug this evidence gap.

¹ When referring to costs, this paper is concerned with the direct costs of housing and support, given the even more limited evidence of impact on wider societal costs and benefits and this paper’s focus on commissioning decisions by health and social care authorities..

² Defining an exact total UK spend on housing and support is difficult. However, data from NHS digital indicates that at least £6.4bn per year is spent on these services by Adult Social Care in England alone. The same source estimates that self-funders additionally spend around 50% of this amount. This suggests that across the UK, the combined spend on residential care and housing and support is likely to be in the region of £12bn – before costs/income from other sources such as housing benefit are factored in.

Recommendation 2. A Fundamental review of registered care regulations to consider how to increase people's rights and control.

Paper 3 described how some housing and support models, in particular registered residential, nursing care and intentional communities, are weak on enabling rights, choice, control and community inclusion (as defined). This is significantly because of the requirements contained within the legal and policy framework for residential (and nursing) care. This paper is not suggesting that the lack of rights, choice and control with (particularly) registered care homes is because of neglect of these issues by providers. Rather it is that the framework that has to exist around residential care, by law and statute, currently removes the capacity for these aspects of personal autonomy to be accorded to people.

In England, CQC guidance on the regulations explicitly notes that people cannot legally own or rent where they live if it is a registered care home. Whilst less clear, the inference of those in Wales and Scotland is the same. This has fundamental implications for the degree of control a person can assert over their living arrangement. Decisions on who comes through the front door, who else lives in the property, the staff to care/support them and indeed whether they continue to live there or are moved on by the decisions of others are all beyond the person's control (or that of their family where mental capacity issues apply). In addition, people who have previously lived with a degree of independence are far more likely to lose this following a move to residential care, meaning that a returning back home becomes far less likely even were it to be considered.

An additional complexity arises from the inter-relationship between registered status and the benefits system. For those in receipt of benefits, being in registered care means having less control over their money and, in practice, less disposable income as benefits are diverted directly to pay for care. For those wishing to work, the inter-action between benefits and income when in residential care means benefitting financially from paid work is practically impossible.

Taken together, these things mean that residential care is, by definition, a service model that accords fewer rights and less personal control. The pay-back for this is argued to be the additional security provided by a more robust regulatory framework. A key question is whether or not it is possible to accord greater rights and personal control whilst still providing supportive regulation i.e. could/should the registered care framework be revised to explicitly enable the greater rights and control that are available through other service models to apply in residential care. (The risk of this is that a concept based on rights and choice might nonetheless become constrained by regulation. We have already seen how the Care Act regulations are using the term 'supported living' to apply non 'normalised'

concepts to it)³. Nonetheless, we believe there is a need for such a fundamental review by Governments. If it were possible to square this circle, the increase in rights and control would be welcomed by many and remove some of the current disincentives around residential care. If not possible, and the current rights and control gap in residential care remains, then the recommendations below become even more important.

Recommendation 3. The provision of independent advocacy and authoritative information to people whom it is proposed move into residential care or similar provision.

A number of years ago, there was a celebrated legal case known as the ‘Alternative Futures’ case. In summary, a provider had arranged for all their residential care services to be changed so people had housing rights and, as a result, the registered status moved to that applicable to domiciliary care. The court ruled that people had not been properly consulted about the impact on them of this change of status, including the loss of some protection through the residential care regulatory framework. The Court was probably right!

However, the reverse also applies. Despite the loss of rights, independence and personal control that is currently unavoidable when moving into residential care rather than living in one’s own home with support, there is no requirement that people receive proper, informed support to consider the consequences of this move. They may well decide that the additional regulatory protection merits the loss of these things – but that should be an informed decision. We therefore recommend that knowledgeable independent and/or peer advocacy, funded by the state, should be made available for every person for whom it is suggested that they move into a residential or nursing home setting, prior to such a move being agreed.

Alongside this should be the provision of evidence based information for people and families considering such a move. This should cover the pros and cons of different housing and support models, including a discussion around implications for rights, choice and community inclusion. At present, the power and knowledge is held (if held anywhere) by professionals and providers – with people being provided with (often glossy) brochures about services on offer. The power in decision making around what services and support to use should shift towards the person and the family.

³ See blog by Lucy Series. <https://thesmallplaces.wordpress.com/2015/02/18/a-stupid-question-about-supported-living/>

Recommendation 4. The development and provision of resources and training to enable commissioners to take more informed decisions about housing and support.

As Papers 2 and 3 showed, the plethora of different housing and support models and their pros and cons is quite complex – doubly so when the evidence (or lack of it) about outcomes and cost effectiveness from Paper 1 is overlaid on it. Our experience suggests that most local authority commissioners are unaware of many of the possible housing and support model options and even less aware of the evidence of impact. The recent Rochdale case⁴ was an example of this. The commissioners there were proposing a fundamental change to services, whilst clearly misunderstanding different models and claiming evidence that did not exist. It required a legal intervention to prevent those changes going ahead.

We therefore recommend that Governments, together with representative bodies of local government and the NHS, invest in a significant programme of work to inform commissioners of the different housing and support options that are available, the evidence base behind them, and the impact of each on rights, choice, control and inclusion. This should include the development of a typology of different approaches (for which we commend that proposed in our Paper 2), and consist of comprehensive materials, training and peer learning opportunities and a clear articulation of the definition and purpose of considering cost effectiveness i.e. the interface between spend and outcomes.

It is particularly important that this involves and engages front line social workers. Individual assessments, generally led/facilitated by social workers, are a prime driver of decisions about types and style of housing and support. Applying a thorough understanding of the evidence base and the range of options available to a genuinely person centred individual planning process could empower social workers to work towards significantly improved outcomes for people.

Recommendation 5. The development and provision of resources and training for providers to enable them to both understand different housing and support options and also to maximise people’s rights, choice, control and community inclusion within the current legal frameworks.

Our experience suggests that a similar lack of awareness about different models and a belief in limited or non-existent evidence applies to many providers. For example, in the course of this series of papers, we have been contacted by providers using inaccurate definitions and asserting evidence of cost effectiveness which, on examination, did not exist. We know from

⁴ <https://www.ndti.org.uk/blog/rochdales-transformation-of-learning-disability-services>

our relationships and work with them that many providers would seize the opportunity to explore different ways of working that increased personal autonomy.

A range of services and support options should be available from which people who use services and their families can choose and so this paper should not be interpreted as arguing for the abolition of any of the different housing and support options described in Paper 2's typology.. As we noted at the outset, we have observed a variety of practice by providers within the legal and policy framework that currently applies. For example, some residential care providers require staff and organisational practice that gives people greater control over how they live their lives and who supports them. Equally, some providers of shared supported housing continue to mimic traditional residential care practice, so that rights exist on paper but not in reality.

As a start, the materials from Recommendation 4 should also being made available to housing and support providers. We additionally recommend that Governments and representative bodies of commissioners and providers should work together to develop and promote best practice materials and knowledge about how, within the current legal framework, providers (with support from commissioners) can change their practice and service design in order to increase rights, choice, control and community inclusion.

Recommendation 6. Amend, clarify and strengthen regulatory responsibilities

Regulators (CQC, CSSIW, Care Inspectorate [Scotland] and the Regulation and Quality Improvement Authority [Northern Ireland]) have an important role to play here. We know that at least some of the regulators are unhappy about the limitations on what they can do and have sought advice on how they can empower more evidence based commissioning and provision.

There are, of course, different regulatory frameworks in the different countries of the UK. We recommend, that either individually or collaboratively, the different governments and their regulators consult with commissioners, providers and the voices of people who use services to produce proposals for how the regulatory system can help to improve the following outcomes from housing and support:

- An increased commissioner (and thus provider) focus on outcomes. Where regulators cover commissioners, this could include monitoring evidence of how commissioners are contractually requiring providers to evidence the quality of life outcomes for people. Where regulators only cover providers (i.e. England), then inspections could review the quality and content of contracts and publicly comment on different authorities concern for and attention to outcomes.

- An increased focus by both commissioners and providers on community inclusion and promoting independence. The outcomes and factors considered by regulators should pay greater attention to life, relationships and involvement outside the boundaries of the formal care setting.
- Tenancies and housing rights being enforced. The care regulators should be empowered to look at and comment on whether the rights people have (both housing rights and human rights) are being delivered in practice by residential care, housing and support providers. Where rights are being denied, sanctions should be applied and remedial enforcement action taken. The Homes and Communities Agency (and its equivalents in all UK countries) should be required to be party to this and take action where their regulated housing providers are issuing tenancies that are not being honoured by care and support agencies.



Summary and Conclusion

The two related core issues being addressed in this paper are the lack of robust evidence about the cost effectiveness of different housing and support options for disabled and older people and how, in the absence of that, commissioners and providers are taking flawed decisions in the belief that some models are more or less effective than others. As a result, disabled and older people are being denied access to the types of housing and support that we know from effective coproduction, they really want.

This series of four papers from NDTi has sought to demonstrate how this situation has arisen from the inter-play of three factors:

- A lack of investment in research and evidence gathering that would help more informed decision making
- The absence of commonly accepted definitions and understanding of different housing and support models
- The limited voice of people who use services and their families in the decision making around what services are available to them

We would suggest that these factors, in the current economic climate, are leading to service decision makers increasingly placing price as a priority over rights, control and community inclusion – despite the lack of evidence about cost-effectiveness.

Our recommendations are grounded in the evidence and experience we have of working to promote better outcomes from housing and support for people with a range of support needs. We do not suggest these six ideas are perfect or comprehensive. We offer them as a contribution to debate and very much hope that people with an interest or role in housing and support for disabled and/or older people will respond with their own thoughts and comments through the on-line discussion forum or through direct contact with NDTi.

We hope, and believe, that this is just the start of an ongoing debate about this important subject area.