# 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.

This includes people having choice and control over where they live and the support that they receive. Through our work across the UK with older people, people with learning disabilities and people with mental health problems it has become clear that despite the range of housing options that exists for people with support needs, there is still an over reliance on traditional forms of housing and support such as residential or nursing care.

Although current health and social care policy and legislation emphasises person-centred approaches and use of community based options (e.g. the Care Act 2014), and discourages residential settings which are segregated from family and communities, this does not appear to be having a significant impact on current patterns. Indeed, it appears that we are currently seeing a shift away from options that offer choice and control, towards more traditional residential care – with these developments being implemented on the rationale that residential care is lower cost.

In order to stimulate debate about the continued over reliance and possible increase in use of residential care, and to encourage more serious exploration and consideration of alternative options, NDTi conducted work to scope, define and describe the different housing and support options available for older people, people with learning disabilities and people with mental health problems. From this, we produced a series of short discussion papers which were shared between January and May 2017 and have now been drawn together in this document. They were as follows:

- Paper 1: Cost and cost-effectiveness of housing and support options (January 2017) a summary of the evidence available on the cost and cost-effectiveness of residential care compared to other housing and support options, including highlighting significant limitations in the evidence available
- Paper 2: A proposed typology of housing and support options (February 2017) acknowledging that a lack of common understanding of terms and definitions can limit understanding of alternatives to residential care, we proposed a typology identifying and describing the different housing and support options
- Paper 3: Characteristics of housing and support options (April 2017) in response to feedback and comments on the proposed typology, this paper set out the different characteristics of the housing and support options identified in terms of choice, control, rights and inclusion

• **Paper 4: Policy Recommendations (May 2017)** - drew policy and practice recommendations from the discussion and debate generated from the previous papers.

To assist readers, we have now drawn all four papers into this, consolidated document, with the four papers forming the following four sections.



# Discussion Paper 1: What is the evidence for the cost or cost-effectiveness of housing and support options for people with care or support needs?

In the current climate of funding cuts to social care and increasing pressure on local authorities to reduce spending, cost is an inevitable factor to be considered in decisions around housing and support. Anecdotal evidence of a move away from alternative models of housing and support to more traditional residential care on the basis of cost alone has recently been made explicit in the case of Rochdale Council's savings proposal consultation which seeks a £1.4m saving by "transforming" supported living provision and replacing it with a range of residential care and other services (see here).

In recognition of the current emphasis placed on cost in shaping decisions about housing and support, we start with a summary of a short review of the evidence available on the cost and cost-effectiveness of residential care compared to other housing and support options. We conducted a search of peer reviewed and grey literature from 2000 onwards. Literature was limited to research and studies conducted in the UK and Ireland. We refer to both cost and cost-effectiveness as some studies identify costs only, without also considering effectiveness. It should be highlighted that the time and resource available for the search was limited, therefore the evidence summarised in this section should not be taken as a comprehensive review of all evidence in this area. We invited suggestions of further robust and impartial evidence that we have missed, but nothing substantive was identified by respondents.

Through reviewing the research that the search identified, it became clear that there are significant limitations to the existing evidence on cost and cost-effectiveness. In light of this, we highlight these limitations first, before providing a broad summary of the evidence that is available and what it suggests.

#### Limitations of cost and cost-effectiveness research

Firstly, the research is limited simply in terms of **quantity**. Considering the very significant amount of public funding spent on housing and support, there are relatively few studies which look at the costs of different options, and even fewer which look at their cost-effectiveness. For example, a recently published and otherwise comprehensive academic book which looks at the outcomes of supported housing in Britain and Sweden barely

addresses the cost of supported housing, other than to suggest that supported housing may be less expensive than institutional living (Clapham, 2015).

Secondly, there are limitations around the **quality** of some of the research. Several of the studies identified are costed case studies rather than robust cost or cost-effectiveness comparisons (e.g. Hurstfield et al 2007; Department of Health, 2009; The Association of Supported Living, 2009; Roe et al, 2011). While these can be useful as illustrative examples, they are not robust, reliable research studies on which to base cost-effectiveness decisions. In addition, some of the research and the costed case studies reviewed are not independent, i.e. they are conducted by organisations or bodies providing or representing some of the alternative housing and support providers, raising questions about potential bias.

Thirdly, there are specific issues around the unit costs used in much of the research. There is a tendency for the recycling of unit costs between studies and sources; for example, once a unit cost has been calculated, it can be reused and updated by different authors. The Personal Social Services Research Unit (PSSRU) 'Unit Costs of Health and Social Care' (Curtis, and Burns, 2016) which is updated annually, and data published by LaingBuisson are generally considered to be reliable sources of cost data and used in costed studies. While they provide access to some of the best available data, careful examination of some of the methodology behind the original sources of the unit costs reveals they often have their limitations. For example, take the case of the PSSRU unit costs for adults with learning disabilities in residential care and supported living. These are based on illustrative cost models developed by LaingBuisson in 2011 (Roe et al, 2011). The unit cost for residential care homes is based on examples of high-specification care homes in the South East of England (one 4 bed residential house and one 8 bed residential house). The unit costs for supported living homes is based on supported living homes in the North West of England (one 2 bed supported living home and one 3 bed supported living home). The weekly unit costs for the residential care homes include living expenses, whereas the weekly unit costs for supported living homes do not. Not only are these unit costs based on just two homes each, they are in different parts of the country and they include different elements within the weekly unit costs. That these two sources of costs data are considered to be among the most reliable sources of unit costs, emphasises the weakness of the available data on which to base any costed studies. Indeed, the LaingBuisson report itself concludes:

"The need to better understand costs, and the effect of changes in key variables on unit costs, fees, margins and viability, is ongoing and key to making good decisions for the future. Much work still needs to be done." (Roe et al, 2011, p22).

Linked to this is the issue of variation and lack of clarity over what is included in unit costs. Some studies and case examples only include cost to adult social care, rather than cost to the public purse in general. This an issue for making comparisons between housing and support options. For example, the cost of residential or nursing care includes housing and living costs as well as care and support costs, whereas for many other options housing and living costs are separate from care and support costs, but often publicly funded through housing benefit and welfare benefits. When unit costs are presented as a weekly cost, it is often unclear whether they include housing and living costs or solely the cost to adult social care.

Fourthly, making comparisons based on weekly unit costs of different models, which many of the studies do, **ignores future cost benefits** that may accrue for many years as a result of certain housing and support options. Some options may prevent future costs to health and social care (i.e. through improved health or wellbeing, or community inclusion reducing reliance on statutory services) but this is not taken into account when simple comparisons between unit costs are made. On the other hand, a number of studies make ambitious claims about future costs prevented which are very difficult to evidence.

Finally, there are further difficulties when it comes to attempting to make **comparisons** between studies. There are vast differences in the terminology used to describe different housing and support options. This is particularly the case around supported housing/supported accommodation/supported living/independent living/group homes where these terms can refer to similar or very different types of support. This issue is exacerbated by the lack of clear definitions in many of the studies reviewed (i.e. not stating what they mean by the terms they have adopted). Linked to this, a number of the more robust studies classify different housing and support options by staffing levels (particularly in mental health); for example, low level/24 hour staffing rather than the type of housing and support. Furthermore, it is difficult to draw conclusions about a particular model without recognising that the cost can vary hugely depending on the support need of the individual. Within a single primary support need there can be a huge variation in the level of need from low to very high and complex needs meaning it is difficult to come up with satisfactory average costs for one housing and support option.

A recent School for Social Care Research scoping review on housing and adult social care, which included a review of cost and cost-effectiveness research, summarises the problems with the evidence in this area:

"Although there have been a growing number of studies involving some element of cost-effectiveness or value for money analysis, the evidence base is still weak in relation to housing and adult social care and frequently involves some heroic assumptions about the cost offsets or what has been prevented. Major analytical constraints include the availability of comprehensive cost data and the difficulty of costing some benefits, especially ones that accrue over time. Many of the wider costs are difficult to quantify and to attribute to a particular measure... More research is needed to quantify the costs and benefits over time to specific client groups of housing

interventions, which include control or comparator groups, and measures for 'softer' outcomes such as enabling independent living." (Bligh et al, 2015, pp49-50)

#### Summary of review findings

In spite of these quite significant limitations, and the caveats that must come with them, the review conducted reveals some general indications that alternative housing and options can be delivered at similar or lower cost than residential or nursing care.

Very broadly, the evidence for people with mental health problems indicates that either individual or shared supported housing options are lower cost than residential care homes (Jarbrink et al, 2001; Beecham et al, 2004; Priebe et al, 2009; Knapp et al, 2014; Killaspy et al, 2016). For people with a learning disability, the picture is less clear; some studies have suggested that individual or shared supported housing options can be higher cost than residential or nursing homes (Hallam et al, 2006; Roe, 2011a; Roe, 2011b) while others provide examples of supported housing options costing less than residential care (Department of Health, 2009; Association for Supported Living, 2011, McConkey et al, 2016).

There have been several studies which have looked at extra care housing (or very sheltered housing) for older people. Most have found that extra care housing is lower cost or saves money compared to residential care (Nash et al, 2013; Weis and Tuck, 2013; Bield et al, 2013) or is lower or similar cost with more positive outcomes (Netten et al, 2011, Baumker et al, 2011).

A small evaluation of living support networks (e.g. KeyRing) found that they resulted in reduced support costs compared to alternative forms of support (Short, 2009). A number of studies have found that adult placement (most of them Shared Lives) is lower cost than residential care (Beecham at al, 2004; Dickinson, 2011; Roe, 2011; Social Finance, 2013). However, it should also be noted that a recent attempt to look at the costs of Shared Lives for older people highlighted that the range of costs across schemes, the lack of consistent cost information and the difficulty in collecting cost data make it difficult to estimate true costs (Brookes and Callaghan, 2014).

There are indications therefore, that alternative housing and support options which, we argue, offer greater levels of social and community inclusion, choice and control (as is explored in the following sections) can be provided at comparable or lower cost than residential care, but the evidence is both minimal and limited in quality. High quality research which looks at both cost and effectiveness in this area is scarce, and there is a clear need for more robust studies to be carried out.

#### Conclusion of Discussion Paper 1:

To summarise, although we reviewed various research studies which looked at the costs of residential care homes and other forms of housing and support, the issues outlined above have led us to conclude that the limitations in quality and quantity mean that there is not sufficient, reliable evidence on which to inform decisions on the basis of cost. As a result, in our view, this makes drawing any firm conclusions about moving to one form of housing with care or support *on the basis of cost* impossible. Given this lack of evidence (that residential care is more or less expensive than other forms of housing and support), there is a strong argument that decisions about an individual's housing and support should be based on other factors supported in current health and social care policy – rights, inclusion, choice and control. The purpose of the next two sections is firstly to propose a typology to assist in describing these alternative options, and secondly to consider the rights and choice based characteristics of these options.



# Discussion Paper 2: A proposed typology of housing and support options

In our work with older people, people with learning disabilities and people with mental health conditions, one factor that inhibits exploration of alternative housing and support options is a limited awareness of what the different options are. This is exacerbated by the confusing array of terminology used to describe some options, for example supported housing/supported accommodation/supported living/independent living/group homes where these terms can refer to similar or very different types of support.

As a step towards addressing this, we have developed a draft typology which identifies, categorises and briefly describes the housing options available for people with care or support needs who do not live with family. This typology has been developed following a desk-based search to scope all housing and support options for older people, people with learning disabilities and people with mental health problems. It does not include accommodation based options which are not a person's home (e.g. temporary accommodation or accommodation which is primarily for treatment purposes). We have deliberately developed a cross-client group typology on the rationale that, even where an option is currently only or mainly used by one client group, there are few options that could not be considered for people with all needs.

As terminology for different options varies widely between client groups, we have selected terms which best describe the provision. We acknowledge that within in each category and sub category there is a great deal of variation in provision, and that the boundaries between the categories can be blurred.

#### Typology of housing and support options (revised April 2017)

MAIN CATEGORY	SUB-CATEGORY				
Mainstream renting	Private renting				
Rented property open to people with and	Property rented from a private landlord				
without care and support needs	Social housing				
	Property rented from a local authority or				
	housing association				
Home ownership	Owner occupied				
Owned property open to people with and	Property owned outright or with a				
without care and support needs	mortgage				

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	Shared ownership				
	Part owned and part rented property				
	Matched home sharing scheme (e.g.				
	Homeshare)				
	The occupier (typically a home owner)				
	offers free or low-cost accommodation to				
	another person in exchange for an agreed				
	level of support				
Designated shared housing	Shared housing with no support attached				
Shared rented housing for people with	Shared housing for people with care or				
specific care or support needs	support needs where the support provided				
	is separate from the accommodation				
	Shared supported housing				
	Shared housing for people with care or				
	support needs where at least some support				
	is provided by the accommodation provider				
Supported placement	Shared Lives				
Accommodation where the owner or	Someone with care and support needs				
landlord of the property provides some	moves in with a Shared Lives carer as part				
care or support	of a supportive household				
	Supported lodgings				
	Lodgings where the landlord provides a low				
	level of support				
Clustered housing	Sheltered housing				
Self-contained housing for people with	Owned or rented self-contained flats with				
care or support needs, based around a	some communal facilities, and some				
geographical location, sometimes with	services such as an alarm system or warden				
shared facilities, with some level of care or	Extra care				
support provided with the accommodation	Also referred to as 'retirement				
support provided with the accommodation	communities'.				
	Owned or rented self-contained flats with a				
	range of communal facilities, provision for				
	at least some meals, and 24 hour care				
	(usually state funded) available on site				
	through a team of carers				
	Retirement villages				
	Similar to extra care and also referred to as				
	'retirement communities'. Privately funded				
	communities of older people offering a				
	range of accommodation options, extensive				
	services and facilities, typically comprising				
	purpose-built residential units which are				
	owned or rented				
	Close care				
	I louis a that is near an adjacent to a serie				
	Housing that is near or adjacent to a care home - the care home provides personal				

	care services and often allows for a future move to the care home if needed. This can be included in extra care and retirement villages <b>Community support network (e.g. KeyRing)</b> A network of people living in their own home who live in close proximity to each other and provide mutual support. One property in the network is occupied by a volunteer who provides a small amount of support to each member of the network				
Residential home	Residential care home				
A room in a home where meals, care and	A residential home which provides personal				
support are all provided – these can be private, voluntary sector or local authority	care Residential nursing home				
run	A residential home which provides nursing care				
Intentional communities	Co-housing				
A planned residential community in some	Communities created and run by their				
cases based on a common support need	residents. Each household has a self- contained, private home but residents come together to manage their community and share activities				
	Learning disability intentional communities (Usually for people with learning disabilities but occasionally also including people with autism and mental health conditions) Communities set up to provide housing for people with learning disabilities who live together as part of a supportive community. Professional care is replaced with a model based on mutual support and help				
	Therapeutic communities Communities primarily for people with mental health conditions, which focus on rehabilitation and communal living and often encourage individual and group therapy				
Charitable housing	Almshouse				
Other housing schemes run by charities not included in the above categories	Run by charitable trusts, mainly for older people. Each charity has a policy about who it will assist, such as residents in a particular geographical area or workers who have retired from a particular trade				

Gifted housing
Older homeowners can donate their
property to an organisation, in return for
the organisation taking responsibility for
maintenance of the property and giving
help and support to stay living
independently in the home

**Note:** We have not included 'supported living' as a category in this typology. This is because a) it is a term which can include many of the options described above, and b) it is a term that was originally conceived to describe a way of working and living rather than a service model and thus, though often used to describe a model of separate housing and support, its use can be misleading. For a discussion on what supported living is see: www.ndti.org.uk/uploads/files/Supported Living - Making the Move, May 2010.pdf.



# Discussion Paper 3: Characteristics of housing and support options: Inclusion, rights, choice and control

Here we consider the characteristics of the housing and support options identified in terms of the level of inclusion, rights, choice and control they offer to people with care or support needs. Taking the list of housing and support categories identified in the typology, the diagram and table below illustrate the characteristics of the different options.

The first diagram illustrates what the different options offer in terms of a) community location and b) level of choice and control.

(a) Community Location

The housing and support model on its own cannot lead to or block people's inclusion in the community, as that is also significantly influenced by the staff and management practice of the support provider. However, the model can influence the possibility of community inclusion being achieved. The extent to which a person's housing is part of the community, appearing physically and visually to be no different to that of other citizens, will impact on how the person is seen by other community members and thus the potential for them being accepted as an equal community member. We are therefore using **community location** as a proxy for a housing and support model's **potential for inclusion**.

We define the different levels of community location as shown in diagram 1 as:

- Mainstream housing available to anyone whether they have a need for care and support or not, and thus where there is no indication or statement that it is designed for/used by disabled or older people
- Designated housing which is available to people with specific care and support needs and which is located among mainstream housing and communities but where it would be known locally, either because of physical design or clear restriction on use, that it is a property where older people, disabled people, or those with care and support needs live
- Segregated housing which is only available to people with specific care and support needs and which is separated by location from mainstream housing and communities

#### (b) Level of choice and Control

Rights, choice and personal control are important, in part, because the promotion of these things is part of national policy and the legal framework for disabled and older people. From NDTi's perspective, we work to ensure equality between disabled and older people and other citizens. Thus, people having their rights respected, and having genuine choice and control over how to live their life, are important considerations. Housing and support models should thus be designed in order to promote rights, choice and personal control.

Once again, how staff and managers implement service models will impact on rights, choice and control. In order to quantify how different housing and support models meet these requirements, we are consequently focusing on how each model from our typology should deliver people's rights to determine how their care and support is provided. We recognise that there will always be variations within these depending on the approach of those providing care and support.

We define the levels of choice and control in broad terms in diagram 1 against three definitions:

- Full choice of care and support support is completely separate from housing (i.e. if the person moved home they could take support with them, or if the person wanted to change the care/support their housing would not be affected)
- Some choice of care and support some elements of care and support come with the housing (i.e. if the person moved house they would lose the support, or if they did not want the support they would have to move home). It also includes those arrangements where there is a 'matching' prior to moving in so the element of choice is present at that stage
- Minimal choice of care and support all care and support is provided by the accommodation provider, there is minimal choice or control over how the care/support is provided or who it is provided by, and if the person moved home they would lose the care or support

Note that some housing and support options fall into more than one category because of the different ways that the model operates or different ways that support is offered. One of the challenges with categorising the variety of housing and support models in relation to the choice and control afforded is that there can be wide variation within a model and there may be exceptions to the rule. However, the following tables attempt to offer a (potentially) crude but generalised summary of the predominant characteristics of each arrangement.

The second table provides a more detailed list of characteristics (including choice, control, rights, regulations) of the different options and also identifies which population/client groups the options are currently generally available for. One right or control that people should have is access to confidence that the housing and/or support provider will not abuse

or misuse their position and will deliver a good service. Ensuring this is often the responsibility of the regulatory framework. We therefore include, in this table, consideration of whether the arrangements (in their entirety or in part) are CQC regulated (recognising that any independent domiciliary service will be CQC regulated).

#### Diagram 1: Level of inclusion and choice of housing and support options

	Seg	communities Therapeutic communities Minimal choice	Some choice	Full choice
-	Segregated	Sheltered housing Residential care home Residential nursing home Learning disability intentional	Retirement village Extra care Sheltered housing	
INCLUSION OF HOUSING	Designated	Shared supported housing Close care Residential care home Residential nursing home	Shared supported housing Community support network Co-housing	Shared housing with no support attached Almshouse Co-housing
IJ,	Mainstream		Matched home sharing scheme (e.g. Homeshare) Shared Lives Supported lodgings Community support network	Private renting Social housing Owner occupied Shared ownership Gifted housing

LEVEL OF CHOICE OF CARE AND SUPPORT

#### Diagram 2: Characteristics of housing and support options

	Choice over who live with	Choice over nature and type of support	Choice over who supports	Control over what happens in the home	Own front door	Security of tenure	Rights to full welfare benefits	Arrangem ent CQC regulated	Community location	Predomin antly sole or shared	Which client groups generally an option for
Private renting	√	✓	✓	✓	Varies	Partial	✓	x	Mainstream	Either	All
Social housing	✓	✓	✓	✓	✓	✓	✓	Х	Mainstream	Sole	All
Owner occupied	✓	✓	✓	✓	✓	✓	✓	Х	Mainstream	Sole	All
Shared ownership	✓	✓	✓	✓	✓	✓	✓	Х	Mainstream	Sole	All
Gifted housing	✓	✓	✓	✓	✓	✓	✓	Х	Mainstream	Sole	OP
Matched home sharing scheme	Partial	Partial	Partial	✓	✓	✓	✓	✓	Mainstream	Shared	ОР
Shared Lives	Partial	Partial	Partial	Х	х	Х	✓	✓	Mainstream	Shared	All
Supported lodgings	Partial	Partial	Partial	Х	х	Х	✓	х	Mainstream	Shared	LD MH
Community support network	V	Partial	Partial	✓	✓	✓	V	Partial	Mainstream/d esignated	Sole	LD
Shared housing with no support attached	no support Varies 🗸 🖌 Varied x Partial 🖌		x	Designated	Shared	LD MH					
Almshouse	✓	✓	✓	✓	~	х	✓	х	Designated	Sole	OP
Shared supported housing	Varies	Varies	Varies	Partial	х	Partial	✓	Partial	Designated	Shared	LD MH
Close care	✓	х	х	✓	✓	✓	✓	✓	Designated	Sole	OP
Co-housing	Partial	<b>v</b>	~	•	✓	✓	✓	x	Designated/S egregated	Sole	ОР
Retirement village	✓	✓	✓	✓	✓	✓	✓	✓	Segregated	Sole	OP
Extra care	✓	Partial	Partial	✓	✓	✓	✓	✓	Segregated	Sole	LD OP
Sheltered housing	✓	Partial	Partial	✓	✓	✓	✓	Partial	Segregated	Sole	LD OP
Residential care home	x	x	x	х	x	x	Х	V	Designated/se gregated	Shared	All
Residential nursing home	lential nursing home x		x	х	x	x	Х	V	Designated/se gregated	Shared	All
Learning disability intentional communities	x	x	х	х	x	x	V	V	Segregated	Shared	LD
Therapeutic communities	х	х	х	Х	х	х	✓	✓	Segregated	Shared	МН



# Discussion Paper 4: Policy and Practice Recommendations

The recommendations in this paper have been drawn from the discussion and debate generated from the content above.

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

- 1. 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.
- 2. 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.

# 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 spent<sup>1</sup>. 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

<sup>&</sup>lt;sup>1</sup> 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.

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 support<sup>2</sup>, 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.

# 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 with 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.

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<sup>&</sup>lt;sup>2</sup> 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.

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)<sup>3</sup>. 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

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

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.

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 case<sup>4</sup> 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 <u>and</u> 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.

<sup>&</sup>lt;sup>4</sup> <u>www.ndti.org.uk/blog/rochdales-transformation-of-learning-disability-services</u>

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 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.

These 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.



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