



Policy Position on Accommodation-based Care and Support for Adults with Learning Disabilities and/or Autistic Adults

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Purpose

The purpose of this document is to deliver a formal policy position in relation to registration, and variation of existing conditions, for services for adults with learning disabilities and/or autistic adults where the support provided is linked to accommodation.

This position will help stimulate more appropriate care resource within local communities, located and designed in a way that supports active citizenship for people experiencing care. The provision of services for people within their own communities will reduce the likelihood of people having to move away from their chosen community (out of area placements), unless they choose to do so, to receive the support they need.

We believe that the autism and learning disability communities will benefit from the publication of our position, based upon evidence from nationally recognised guidance, good practice, Scottish Government strategy, and in consideration of the [Scottish Regulators' Strategic Code of Practice](#).

This policy position will support the strategy in [The keys to life: Improving Quality of Life for People with Learning Disabilities \(Scottish Government, 2013\)](#), [Learning/Intellectual Disability and Autism - Towards Transformation \(Scottish Government, 2021\)](#), [The national strategy for autistic children, young people and adults: 2021 to 2026 \(Department of Health and Social Care & Department of Education, 2021\)](#) and [The independent review of Learning Disability and Autism in the Mental Health Act \(Rome, Evans & Webster, 2019\)](#) and will be used as part of the decision-making process in our assessment of registration and variation applications.

Summary

We require proposed care homes, and services that provide care and support to enable people to live in their own homes where housing is also provided, to demonstrate that:

- Care and support for adults with learning disabilities and/or autistic adults offers choice and is provided within their own home and community, avoiding enclave/ghetto style developments;
- The size, location and design of proposed care services support inclusion in the community, and are designed to prevent isolation;
- A limit of no more than six places applies to care homes for adults with learning disabilities and/or autistic adults (unless the applicant can demonstrate why more than six places are necessary);
- Genuine co-production has been undertaken.

Where the market case and community interest within the home local authority have not been demonstrated, this will be considered in decisions to register or refuse.

Policy position

Our position is that care and support for adults with learning disabilities and/or autistic adults should offer choice and be provided, where possible, within their own home and community. We expect the design and development of services to be co-produced. Co-production is a way of way of working with, rather than doing to,

people and communities to achieve better service design and outcomes. The service design, size and location, and proposed operation must be in keeping with nationally recognised guidance, good practice, and Scottish Government strategy as detailed throughout this document. It must support living, citizenship and inclusion in the community.

Applicants must demonstrate that the setting, location, size (ideally no more than six places within each newly registered care home service, unless the applicant can demonstrate why more than six places are necessary) and the operation of service supports the **Convention of the Rights of Persons with Disabilities (2006): Article 19 – Living independently and being included in the community:**

States Parties to the present Convention recognise 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, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

In addition, Article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), ratified by the UK, states that everybody has the right to an adequate standard of housing. The Scottish Government's proposed **Human Rights Bill** plans to embed the right to adequate housing in Scots law and the Scottish Government's Housing to 2040 plan includes actions to realise the right to an adequate home in Scotland.

Making the right to an adequate home a reality for people with learning/intellectual disabilities in Accommodation-based Care and Support requires consideration of the following:

- Legal security of tenure
- Availability of services, materials, facilities and infrastructure
- Affordability
- Habitability
- Accessibility
- Location
- Cultural adequacy

It must also be able to meet each individual's need for space, stimulation, sensory needs, activity, outdoor access, contact with others, routine and support.

Care Homes

An application to register a care home service for adults with learning disabilities and/or autistic adults, should, ideally, not exceed 6 places. Applications to vary an existing condition, will be expected to demonstrate small household living of no more than six people, and a focus for adults with learning disabilities and/or autistic adults to promote well-being, opportunity, and citizenship within their local community. Where an applicant is unable to do this, registration, or an application for variation, may be refused in accordance with this policy. Variations to add units for adults with learning disabilities and/or autistic adults to care homes for older people are unlikely to be able to achieve this, and so may be refused in accordance with this policy.

In developing care home services and other community settings for adults with learning disabilities and/or autistic adults we expect applicants and providers to give cognisance to good practice guidance on the environment as referred to in our [Care Homes Design Guide](#) such as:

- [An independent guide to quality care for autistic people \(National Autistic Taskforce, 2019\)](#)
- [Autism spectrum disorder in adults: diagnosis and management](#)
- [National Autistic Society's SPELL Framework](#)

Care Services where Housing is also provided

The development of supported accommodation services in the community for adults with learning disabilities and/or autistic adults, such as core and cluster models, should not be of a design that inhibits social integration and inclusion with the wider community nor creates an enclave or ghetto environment.

Background

To date, we have not had a specific policy regarding accommodation-based care and support for adults with learning disabilities and/or autistic adults. Instead, we have relied on [The Social Care and Social Work Improvement Scotland \(Requirements for Care Services\) Regulations 2011, regulations 4 and 10](#) to support us in our assessment of registration and variation applications in relation to a rights based approach informing the building, design, size and location of services which are linked to accommodation such as care homes or supported housing developments.

Since 2018 there has been a rise in pre-registration advice and applications for care homes for adults with learning disabilities and/or autistic adults, and for the enlargement of some already in existence. This is concerning because we know from a range of guidance, strategy, and best practice documents, as referred to throughout this document, that increased provision and size does not always equal increased quality. We also noted a trend towards adding units to care homes for older people; this decreases the likelihood of services being able to meet the individual needs of people using the service.

Evidence from inspections demonstrates a decrease in positive outcomes for adults with learning disabilities and/or autistic adults who are living in care homes. Despite the numbers of care homes for adults with learning disabilities remaining largely the same (from 155 in March 2019 to 153 in March 2021) the percentage of services

graded at 'good' or better decreased from 83% in March 2019, to 78% in March 2020, and 76% in March 2021.

There have been some care homes where adults with learning disabilities and/or autistic adults are living with people who do not have learning disabilities and/or autism, but another care need such as mental health or care associated with older age. This environment does not support the particular focus of care; it does not promote independence or individual development. It is not sufficient to suggest that people with differing disabilities and care needs live within communities as each person living in their own home is able to adapt their housing to suit their own needs. This is not the case for a care home where facilities such as sitting and dining rooms, bathrooms and kitchens are shared, which is why it is important that the environment is suitable to meet the needs of the people experiencing care.

Rationale

Our decision to move to this policy position has been informed by a range of evidence from nationally recognised guidance, good practice, and Scottish Government strategy, not least the Care Quality Commission (CQC) document [Right support, right care, right culture \(CQC, 2020\)](#) which stated:

“Autistic people and people with a learning disability are as entitled to live an ordinary life as any other citizen. We expect health and social care providers to guarantee autistic people and people with a learning disability the choices, dignity, independence and good access to local communities that most people take for granted.”

This document clearly articulated this regulator’s position and the factors that would make it more likely that applications to register or vary registration would be granted by them e.g. that:

1. There is a clear need for the service and it has been agreed by commissioners
2. The size, setting and design of the service meet people’s expectations and align with current best practice
3. People have supported access and involvement in the community
4. The model of care, policies and procedures are in line with current best practice

It built on their document [Registering the right support \(CQC, 2017\)](#) which restricts provision for adults with learning disabilities and/or autistic adults to six places, but does consider larger size services if providers demonstrate best practice in keeping with relevant guidance and government strategy ([Building the right support \(LGA, ADASS & NHEngland, 2015\)](#)). This is a position which was based on [Autism spectrum disorder in adults: diagnosis and management \(NICE, 2016\)](#). It specified:

“If residential care is needed for adults with autism it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation).”

Principles – rights-based approach

A rights-based approach places the person at the centre of their choice and selection of the best care service for them and includes choice about where they want to live

and who they may want to live with. It is important that the Care Inspectorate supports growth and availability of services within a rights-based approach. Economy of scale should not be the overriding factor.

As noted in [The keys to life: Improving Quality of Life for People with Learning Disabilities \(Scottish Government, 2013\)](#), most people live in ordinary housing and that is where they want to stay. **Living in your own home is a human right and the expected outcome.** In exceptional circumstances for those who need particular specialist support or do not wish to live alone or to have their own tenancy, registration of care homes for adults with learning disabilities and/or autistic adults must be designed to promote as much independence in daily life as possible and with an environment that supports each person's development through their life (e.g. [Health and Social Care Standards \(2017\)](#) 1.22, 2.2, and 5.11). To promote inclusion and prevent perceived segregation, size should be small. People with very high care and support needs are the only group where care home provision could be justified ([The same as you? A review of services for people with learning disabilities \(SCLD and Scottish Government, 2012\)](#)).

Principles – community integration

[Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs \(Scottish Government, 2018\)](#) explained the importance of social care providers successfully supporting people who may have complex social, physical and psychological needs in a manner that supports genuine citizenship. It explained:

“Large institutional services should not be seen as the way forward, and in particular former institutions should not be re-commissioned and badged as community living, unless that is what they genuinely provide.”

We consider community living to mean people having a life which is fully integrated into the **local community of their choice**. It should not be simplified to mean discharge from hospital. Out of area placements should not be considered as part of routine referral processes. There should be additional procedures that consider assessment, risk of isolation, planning within the first month and review of social connections. As discussed in [Community Connection and Citizenship \(The Centre for Welfare Reform, 2013\)](#):

“Public services exist to support active citizenship and enhance the contribution of people with learning disabilities to community life.”

To achieve genuine community integration it is critical that individuals are supported to lead full and meaningful lives. Accommodation-based care and support services have a responsibility to accommodate individuals' preferences and aspirations and support them to achieve these. This includes supporting people to maintain a strong network of family, friends, circles of support and to engage in regular meaningful activity and frequent leisure time; in short, a private and family life.

It can be a greater challenge for people with learning disabilities to achieve full citizenship in a care home and, in particular, a large care home. No care home setting could provide a person with 'control over everything that happens there' or allow them to take complete control of their life. Some of the Keys to Citizenship such as people with learning disabilities being supported to meet their goals, being active and visible members of their local community, and developing a range of

relationships can be achieved in a smaller care home where staff have the time and resources. However, in a larger home there is not always the number of staff, training and expertise, resources or flexibility to support all service users to achieve this.

The Social Care (Self-directed Support) (Scotland) Act 2013 directed local authorities to promote the options of self-directed support and make available to people in need of services a wide range of support from a variety of providers and through a variety of support options. The Scottish Commission for People with Learning Disabilities (SCLD), on behalf of the Scottish Government, commissioned the research paper **Improving Outcomes for People with Learning Disabilities: Opportunities and Challenges for Housing (SCLD, 2017)**. This raised concerns that people were being offered shared tenancies and some who were living independently were offered care home accommodation to save money. It noted that people with complex needs perceived as challenging were at risk of missing out on housing options advice and were the most vulnerable to moving to hospital or residential care. Integrated partnerships need to take into account that promoting and using larger care homes to manage delayed discharge is not the direction of travel for quality services. There is a need to promote sufficient and appropriate services in the community which are able to meet complex needs.

Principles – care home design

Generic care homes face a greater challenge in designing a suitable care environment “for all”. A care focus assists designers to incorporate suitable features into the building. Knowledge of the impact of the environment on people living with disabilities has broadened and resulted in resources that identify ways to improve and minimise environmental stress for those experiencing specific disabilities (e.g. **Autism spectrum disorder in adults: diagnosis and management (NICE, 2016); National Autistic Society’s SPELL Framework; An independent guide to quality care for autistic people (National Autistic Taskforce, 2019)**). These resources indicate that one size does not fit all. A care home environment should not only be seen as the physical building but also the culture and society within which a person lives and experiences citizenship (e.g. **Health and Social Care Standards (2017)** 1.10, and 5.9).

It is critical to consider to what extent a care home service can demonstrate an understanding that adults with learning disabilities and/or autistic adults are not a homogenous group but rather a diverse population with varying needs.

In line with **Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs (Scottish Government, 2018)**, suitable accommodation and support solutions for those with complex needs should be determined through a person-centred approach by listening to what each individual needs to live their own life; and building accommodation, care and support based on those needs. There is no ‘one size fits all’ solution, and decisions should not be based on cost savings or economies of scale.

This necessitates highly individualised, flexible, responsive approaches, and should be underpinned by a person-centred care and support plan designed to meet individuals’ outcomes and provide them with the life choices and opportunities that they wish. See our **Guide for Providers on Personal Planning** for more on this. It should uphold the rights of individuals by ensuring that they are able to exercise maximum choice and control over their accommodation, care and support and that

they are treated with dignity and respect. Every effort must be made to provide information about care and support in formats individuals and families can understand to maximise their involvement in decisions around their accommodation, care and support.

The **Health and Social Care Standards (2017)** expect that settings are designed to be homely and provide small group living. The interpretation of this in some cases has remained that of large buildings subdivided into smaller units. This is not in keeping with the spirit of small group living. Grading data demonstrates that smaller care homes are more likely to achieve minimum grades of very good compared to larger care homes.

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