

Do housing  
rights **REALLY**  
exist for  
everyone?







# Hello from us



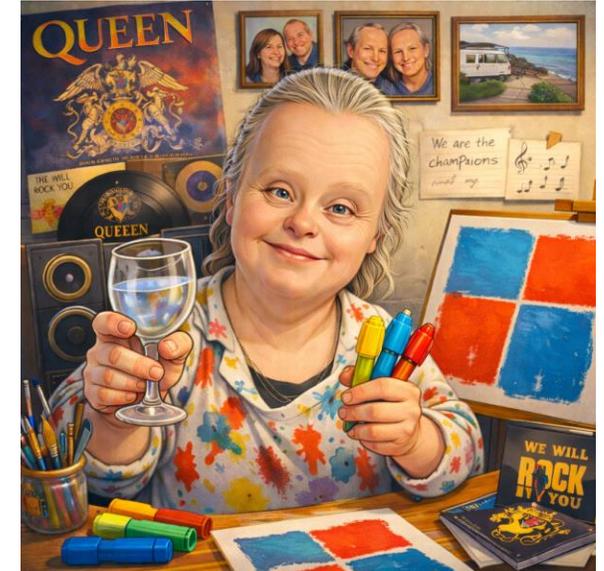
**Mary**

A nurse who has spent time with people with a learning disability her entire life. Charity manager, volunteer, inclusive drama group leader and a sibling of someone with a learning disability.



**Angela**

A nurse for people with a learning disability and Learning Disability Representative Body member. When I Get Old (WIGO). TLAP and Community Catalysts Associate.



**Amy**

A music loving artist. Is a lovely friend and is close to her family. Enjoys holidays, time with people, theatre and good food and wine.

# Supported living

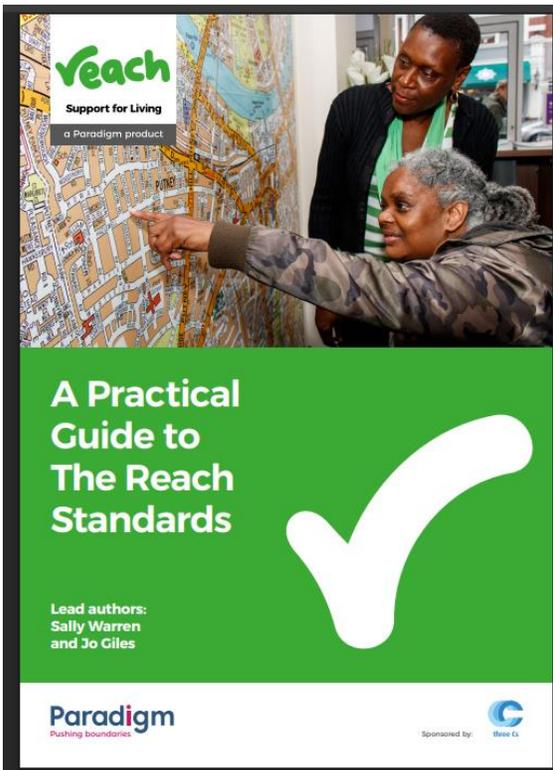
In the UK, supported living for people with a learning disability is a model where someone has their own home (usually with a tenancy or ownership) and receives separate, flexible support [1](#)[2](#)[3](#)

## Key elements of supported living

- **The person lives in “ordinary” housing:** their own flat or house, or a small shared house with a few other people. [4](#)[2](#)[1](#)
- **Housing and support are contractually separate:** the person has a tenancy or licence with a landlord, and a separate agreement with a support provider. [2](#)[3](#)[1](#)
- **Choice and control:** the person chooses where they live, who they live with, and how their support is organised, person-centred planning is core. [5](#)[4](#)[1](#)[2](#)
- **Focus on independence and community life:** support aims to help the person run their home, manage money, develop skills, work or volunteer, and take part in community and social activities. [6](#)[7](#)[4](#)[1](#)
- **Rights as a tenant or owner:** people have the same legal housing rights as other citizens, including security of tenure and the right to change support without automatically losing their home. [3](#)[6](#)[2](#)

## **200 Lives** – a 2022 report into Supported Living and residential care

Of the £5.6 billion spent in 2020/21 on long term social care for adults with learning disabilities aged 18-64, £1.66 billion (30%) was spent on supported living...



**'Our goal is to see people with learning disabilities in the mainstream of life, living in ordinary houses and ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other members... of their own community.'**

Towell D (1988) *'An Ordinary Life in Practice: Developing Comprehensive Community-based Services for People with Learning Disabilities'* London: **The King's Fund**



The concept of Supported Living started in the UK in the 1990s. It is defined in a set of principles called the Reach Standards in Supported Living.

They are rooted in Human Rights principles

## **200 Lives** – a 2022 report into Supported Living and residential care

*Supported living refers to a housing model where the person owns or rents their home, with accommodation and support being provided separately so that the person can change their support provider without affecting their housing or vice versa.*

# Amy's story - good times

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- Lived at home with Mum and Dad for 48 years
- Moved into her own place with 2 friends 16 years ago
- Chose the décor and furniture together – it was fun
- Helped identify a ‘provider’ and to recruit staff who would support
- Provider proud to say Amy could ‘age in place’ and that support would flex and change as she did
- Long term assured tenancy for 15 years – housing separate from support - most REACH standards met
- Happy at home for many years – hobbies, out during the day, friends, control, good support and brilliant housemates



# Amy's story – bad times

- Care provider changed its ethos. High staff turnover. Lots of strangers. House became less happy.
- Covid didn't help
- Amy became unwell and didn't sleep – provider decided 'dementia' – people who love Amy disagreed
- Provider decided Amy needed to move out – people who love Amy disagreed
- Social care and health professionals agreed with the provider. Housing association absent.
- Amy forced to move. Horrid times. Amy and family traumatised
- Requests to 'change the provider' were dismissed. In practice Amy's rights to do this did not exist
- No one in the system even mentioned, let alone fought for, Amy's housing rights. The REACH standards absent



# Amy's story – now

Hooray for a happy ending!

Amy now lives in a new place

Friends and fun

She is back to her old self and happy

'Dementia' disappeared!





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And Amy does  
not seem to be  
alone

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## Bill

Bill has a learning disability and lives with a small group of friends. He has a tenancy and support from a care provider. He has epilepsy and recently his seizures increased in frequency and severity.

His care provider's first response was that Bill would need to move out of his home and go somewhere else because *'staff didn't have the training to deal with that!'*

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# Fatima

Fatima lived with 2 friends. She had a tenancy and help from a care provider. She got degenerative illness and became less physically able.

Rather than make adaptations to the house and the support on offer the care provider said *'her needs are now too high for supported living'*.

There was a discussion about changing provider but because one of her housemates was happy with the status quo the professionals said a change couldn't be made.

Fatima was asked to leave

She now lives in a large care home for older people.





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BUT what is the point  
of rights IF you can't  
stand up for them  
yourself AND  
(crucially) no one  
stands up for them on  
your behalf?





## Key issues we think we see

- Bumps in life's road – health or ageing or...
- Care providers assuming more power than they legally have
- People with a learning disability not able to advocate for their own rights. Families and friends not always aware of people's rights – don't or can't advocate on the person's behalf. Or get ignored!
- The wider system – e.g. social workers, nurses not focussed on housing rights
- Housing associations/landlords absent and/or deferring to the care provider
- No national statistics to measure how big an issue this is

AND its all so  
blinking  
complicated!!!

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# Question one

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How common is this issue?

Do you have personal experience or know people it has happened to?



# Question two

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What can **we** do to make sure housing rights are real and protected for everyone?





# Next steps



# References

1. <https://www.scie.org.uk/housing/role-of-housing/promising-practice/models/supported-living/>
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9. <https://www.achievetogether.co.uk/our-services/supported-living/>
10. <https://www.affinitytrust.org/what-we-do/supported-living/>

# Contact us via



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## **200 Lives** – a 2022 report into Supported Living and residential care

*Despite people in supported living talking about greater self-determination and evidence of higher levels of day-to-day choices, it seems they still have limited control over their housing situations and support with significant proportions of people not having any choice about moving, where they live, who they live with and who provides their support (Bigby et al., 2017; Salmon et al., 2019)*