

Rethinking the Model: Residential & supported living, what has been learned?



In summary

- The dominant policy for 60 years has been inclusion and community care.
- Funding and responsibility moved from NHS to Local Authorities.
- There is evidence that the quality of life for people with learning disability can be improved when the services are appropriate
- One model does not fit all and families are not always well served.
- Much residential provision is now in the charity and private sectors.
- Obtaining and retaining service is a battle most parents face.
- There are examples of parents setting up their own provision.
- The learning disabled and their families struggle to compete for Local Authority funding against the growing numbers of looked after children, people with other disabilities and the frail elderly.
- Rescare stands for choice.

1 Definition of Services

Supported living is the term given by Local Authorities to offer people their 'own homes' via a tenancy or home ownership or shared ownership and have personal and housing related support provided by an outside organisation.

Residential care is when someone lives in a registered care home which is managed and run by a care provider who is responsible for all aspects of their daily needs and wellbeing.¹

A key difference between the two types of services is how an individual's funding package is put together and who is responsible for ultimately spending that money.

Supported Living:

Individuals have a legal right to access a range of benefits

They have access to other sources of funding, including Direct Payments, Supporting People Monies, Independent Living Fund, etc.

They can choose to spend their benefits package on whatever services they like

Spending is monitored and if money is spent inappropriately, action is taken

This also allows people to make choices about the balance between what they spend their money on

Residential Care:

Funding goes to the provider who is responsible for delivering the individualised services

The type and level of these services are pre-determined and are legally binding

Contracts and outcomes are monitored to ensure service quality

Continuing funding of placement is outcome based

Individuals are entitled to limited benefits

(The above is from <https://www.createdbyparents.com/spotlight-on/residential-care-vs-supported-living/> Home From Home Care, An organisation set up by parents unable to find suitable accommodation for their child. They are not alone.

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2 The policy framework over time

In 1971, the White Paper Better Services for the Mentally Handicapped was introduced in Great Britain. The white paper noted that there was a shortage of appropriate residential accommodation for 'mentally handicapped' people, as well as shortages of social workers and training centres. This meant that many parts of the country had minimal facilities for non-hospital care, with hospitals under pressure to admit more patients to overcrowded and unsuitable facilities. The paper had targets. It advocated a 50% reduction in hospital places by 1991 and an increase in the provision of local and community care.

2001 saw the development of philosophy and ambition underpinning policy Valuing People A New Strategy for Learning Disability for the 21st Century A White Paper of local authority-based residential and day care. Says:

“People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. Valuing People sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.

Also the emergence of the problems and challenges

“There are about 210,000 people with severe learning disabilities in England, and about 1.2 million with a mild or moderate disability. Health and social services expenditure on services for adults with learning disabilities stands at around £3 billion. In the 30 years since the last White Paper Better Services for the Mentally Handicapped, progress has been made in closing large institutions and developing services in the community, but more needs to be done.” https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

2010 Valuing People Now Published after a change of government “*recognised the important role that local Partnership Boards can play as effective agents for change in assessing and bench marking local progress and influencing local strategic planning and commissioning*” and stated “*this cross-government strategy laid out the vision that all people with learning disabilities have the right to lead their lives like any others, with the same opportunities and responsibilities, with the right support to make this possible and to be treated with the same dignity and respect.*” https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

Over time this policy had brought to the fore the responsibilities of Local Authorities with the Health Authorities having a much less significant place in official thinking. Access to Local Authority assessments, facilities and funding are therefore now the key for families.

3 The Care Act

The Care Act 2014 came into force on the 1st of April, 2015. It replaced the majority of law and guidance in community care that existed up until that date.

Under the Care Act, local authorities must: carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care. focus

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the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve. A useful Factsheet can be found at:

<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>

The Act itself is at: <https://www.legislation.gov.uk/ukpga/2014/23/enacted>

However, during the pandemic local authorities can use the new Care Act easements, created under the Coronavirus Act 2020, This situation is still evolving.

4 Closing the large hospitals and the aftermath

Initially there was evidence that this policy was indeed capable of proving improved service. For instance Emmerson E, Roberstson J, Gregory N et al 2000² *“The costs, nature, and benefits of residential supports were examined for 86 adults with mental retardation living in village communities, 133 adults living in newly built residential campuses, and 281 adults living in dispersed housing schemes (small community-based group homes and supported living). Results indicated that (a) the adjusted comprehensive costs of provision in dispersed housing schemes were 15% higher than in residential campuses and 20% higher than in village communities; (b) dispersed housing schemes and village communities offered a significantly greater quality of care than did residential campuses; and (c) there appeared to be distinct patterns of quality of life benefits associated with dispersed housing schemes and village communities, with both approaches offering a greater quality of life than did residential campuses”*.

However the practical implications of this policy were critiqued in 2008. A review of the then growing evidence demonstrated³

- High quality community care is not cheaper than hospital care. Researchers found that while some types of living accommodation were cheaper than a hospital place, on average new types of accommodation were more expensive.
- Local authority responsibility for learning disability services has meant that there continued to be a wide variation in the type and quality of services available
- Financial pressures on the private care sector have led to many smaller providers going out of business, to be replaced by larger firms.

⁴ A later review in 2015 *Shared-Life Communities for People with a Learning Disability: A Review of Evidence* commented on an emerging and complex picture

The choice of residence is defined as a right of disabled people under the United Nations Convention on the Rights of Disabled People. Nevertheless, the choice of how and where to live has usually been denied to people with a learning disability. Instead, public policy has usually specified what pattern of life people with a learning disability ought to lead, and research has often discounted their expressed preferences.

There has been very little research on the housing preferences of people with a learning disability, but one recent study of older people with a learning disability found they preferred models of housing that provide an opportunity for people with a learning disability “to live in close proximity to their peers and in large groups in the community rather than in small, dispersed community housing”⁵

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5 Ideas underpinning policy

The enduring ethos behind much of this focus away from group care is exemplified by David Towel (Centre for Welfare Reform 2012) ⁶ who explains that *using the status of the King's Fund, I and my colleagues were able to bring together allies to advance an alternative philosophy. We want 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'*

Reality has been somewhat different Towel continues:

Despite better support to families, this frequently remains inadequate for them to live ordinary lives like other families. Second, for many people with learning disabilities, presence in the community has not equated to full participation, for example in education, employment and leisure opportunities – and many still report lifetimes of loneliness and discrimination. Third, these weaknesses are now being magnified as the government's response to the global financial crisis leads to cuts in public expenditure on both services and welfare benefits. Moreover, this chilly climate may also be weakening the capacity of local communities as sources of mutual support, including for their disadvantaged members.

6 Outcomes

⁷ Also it seems wherever people are housed, learning disability is still associated with disadvantage. In 2015 Elizabeth Blow wrote:

There are 1.5 million people in the UK with a learning disability. When also including families and carers of people with a learning disability, it is estimated around 6 million people in the UK are directly affected. The availability and quality of services for people with a learning disability have recently come under scrutiny. It has also been evidenced that people with a learning disability experience worse outcomes than average, such as poorer access to health services and higher rates of premature mortality.

Also the Learning Disabilities Observatory⁸ reports that information from a range of sources consistently says that people with learning disabilities in England die much younger than the general population (13 to 20 years younger for men with learning disabilities; 20 to 26 years younger for women with People with learning disabilities in England 2015: Main report 5 learning disabilities). As with the general population, the median age of death for people with learning disabilities is increasing. More than three times the number of people with learning disabilities die sooner than would be expected when taking into account age and sex. The three most common causes of death for people with learning disabilities are circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%).

7 Access to Service can be problematic for families

For example Unlawful restrictions on the rights of disabled children with autism to social care needs assessments Luke Clements and colleagues⁹. They say the following *'It is concerning that those in control of providing the support disabled children are entitled to, are breaking the law by having policies in place that restrict access to those that need it. The figures and experiences we have come across are disheartening and show that this problem is widespread. Without sufficient and adequate support in place, children and families are*

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often pushed to breaking point because of the barriers presented to them. The Children Act 1989 provides that disabled children are entitled to services that meet their needs, and therefore policies which prevent this from happening need to be urgently reviewed

Moreover, Clements noting a service which *is primarily concerned with the duties to safeguard children from abuse and neglect and provides only limited practical advice concerning the provision of support to disabled children and their families.*

8 The learning disabled are only a very small proportion for local authorities

Of the overall supported accommodation picture for local authorities; people in supported accommodation versus older people in England, Wales and Scotland, were older people (65+) 395,000 **71%** whereas people with learning disabilities were 38,500 **7%**.¹⁰ . We at Rescare can appreciate the problem of visibility.

9 Implementing good practice

The full implications of an effective service were outlined by the National Institute for Health and Care Excellence in 2015.¹¹

They point out that local authorities and NHS organisations need to assess the resource implications of implementing the NICE guidance on challenging behaviour and learning disabilities locally. They say that the:

Potential areas for additional costs locally are

- the cost of providing care in a person's home or as close to it as possible
- the cost of providing services locally, including training and developing a suitable workforce
- the cost impact of improved care pathways
- the cost of offering a range of psychological interventions and only considering medication for people with a learning disability and behaviour that challenges if other interventions have not produced a change.

Potential areas for savings and benefits locally are

- improved quality of life for the person, and their family members or carers
- a reduction in inappropriate out-of-area placements
- a reduction in inappropriate medication
- a reduction in admissions to hospital and length of stay in hospital.

References

¹ Residential care v supported living <https://www.createdbyparents.com/spotlight-on/residential-care-vs-supported-living/>

² Emmerson E, Roberstson J, Gregory N et al 2000 AJMR 205 no 2 81-102

³ J Walmsley *From care to citizenship?* Chapter 27 From care to citizenship? Jan Walmsley (2008) from Understanding Health and Social care an Introductory Reader: https://www.open.edu/openlearn/ocw/pluginfile.php/638334/mod_resource/content/1/chapter27.pdf

⁴ *Shared-Life Communities for People with a Learning Disability: A Review of Evidence* 2015 Dr Stuart Cumella <https://www.centreforwelfarereform.org/uploads/attachment/481/sharedlife-communities.pdf>

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⁵ Shaw K, Cartwright C and Craig J (2011) *The housing and support needs of people with an intellectual disability into older age*. Journal of Intellectual Disability Research, 55(9), 895-903.

⁶ <https://www.centreforwelfarereform.org/uploads/attachment/362/delivering-the-promise-of-an-ordinary-life.pdf>

⁷ 2015 Learning Disability - policies and issues Standard Note: SN/SP/07058 Last updated: 16 February Author: Elizabeth Blow Section Social Policy Section

⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

⁹ S Broach and L Clements *Disabled children a legal handbook 3rd edition* Legal Action Group (2020) paras 3.33 – 3.34 and <https://cerebra.org.uk/research/unlawful-restrictions-on-the-rights-of-disabled-children-with-autism-to-social-care-needs-assessments/>

¹⁰ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

¹¹ <https://www.nice.org.uk/guidance/ng11/resources/costing-statement-pdf-70691581>

Helpful Resources

Mencap https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf

NICE Guidance <https://www.nice.org.uk/guidance/ng11/resources/costing-statement-pdf-70691581>

Learning Disabilities Observatory People with learning disabilities in England 2015: Main report Version 1.0/ November 2016

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

Further background from our facilitators

https://www.researchgate.net/publication/12561583_Quality_and_Costs_of_Community-Based_Residential_Supports_Village_Communities_and_Residential_Campuses_in_the_United_Kingdom

https://www.ndti.org.uk/assets/files/Housing_research_findings_Final.pdf

<https://www.ndti.org.uk/assets/files/The-Hidden-Cost-of-Support.pdf>