



How-to guide 5 housing

For people with profound and multiple learning disabilities

Raising
our Sights



Raising our Sights guide to housing

Raising our Sights, by Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with profound and multiple learning disabilities (PMLD)¹ and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

Some local areas have started to carry out recommendations from the report. However, many areas have yet to begin and have asked for further guidance on how to do this.

Now that local health and wellbeing boards are starting to lead the commissioning of health and social care services, it is a good time to think about what good support for people with PMLD looks like. It is an opportunity to ensure the right services are commissioned to meet the needs of a group of people who have so often been left out.

These how-to guides were commissioned by the Department of Health, and produced by Mencap and the PMLD Network, to help local areas implement the *Raising our Sights* recommendations, which are aimed at the local level. It does not focus on recommendations aimed at government and national bodies.

About this guide

This guide to housing is one of 11 guides designed to help local areas implement the *Raising our Sights* recommendations. It is for both families and commissioners. For more information about *Raising our Sights*, and to download all the guides, go to:

www.mencap.org.uk/raisingoursights

Sections in this guide

1. What *Raising our Sights* says about housing
2. What does 'good' look like?
3. What needs to be in place to meet the housing needs of people with profound and multiple learning disabilities
4. How can people access suitable housing?
5. Detailed case study
6. Film
7. Frequently asked questions
8. Share good practice!
9. Links to further information and resources

¹ Read the PMLD Network definition of profound and multiple learning disabilities at www.pmldnetwork.org

1. What Raising our Sights says about housing

There are two recommendations:

Recommendation 7.

The government should revise arrangements for capital subsidy from the Homes and Communities Agency to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities.

Recommendation 8.

The government should resolve the apparent contradiction between social care policy and housing policy created by the Turnbull judgement to facilitate the provision of adequate housing for adults with profound intellectual and multiple disabilities.

We know that many people with a learning disability are getting more personalised housing and support options. However, we also know that those with the most complex housing needs, for example people with profound and multiple learning disabilities (PMLD), are often being left out of this.

Mencap's *Housing for people with a learning disability* report, 2012, found that 76% of local authorities reported they have had difficulty arranging housing for adults with PMLD, whereas only 29% reported difficulties arranging housing for people with a mild learning disability.

The *Raising our Sights* recommendations around housing are directed at national government. They aim to address aspects of regulation and policy which are currently acting as barriers to people with PMLD accessing suitable housing. However, there is much that commissioners and housing providers can do on a local level to facilitate availability and access to suitable housing for people with PMLD.

This guide will help local areas understand and meet the housing needs of people with PMLD. It focuses on what 'good' looks like and what needs to be in place to make this happen.

This is a practical guide to support families of people with PMLD and those who plan and commission housing and care services. It will help them work within the current economic and political climate to make housing and

care happen for people with the most complex housing needs.

2. What does 'good' look like?

People with profound and multiple learning disabilities (PMLD) have very complex housing needs that tend to fall into three main categories:

- **the physical** environment including adaptations, equipment and the space needed to meet the person's needs
- **the location** of the housing to allow people to remain close to family, friends and their communities
- **wherever they** are living, the person will need individualised and skilled support for their health, social and wellbeing needs from appropriately trained staff.

When we talk about good housing, we mean that people with PMLD can access a range of options, including both ordinary and specialist housing, which meets their needs. Some types of housing include support.

There is no one model of housing and care that is right for everybody. However, we know that with a person-centred approach to planning, people with PMLD can and do live successfully in a range of different housing including:

- supported housing
- extra care housing
- shared lives
- residential care
- home ownership
- different types of tenancies.

3. What needs to be put in place to meet the housing needs of people with profound and multiple learning disabilities

Commissioners, social care services and housing providers should consider the housing and support needs of people with profound and multiple learning disabilities (PMLD) when they plan and commission different types of housing.

Supported housing

Supported housing is a tenancy with support provided. It can be in shared accommodation or individual flats. Most supported housing developed in recent years has been aimed at people with mild to moderate learning disabilities but there is no reason why it cannot work for people with PMLD if it includes the right physical adaptations and support.

Extra care housing

Extra care housing is based on the sheltered housing model with individual flats and communal space. It was developed to enable older people to remain in their homes and avoid residential care if and when they require

extra care, but can work well for people with PMLD. Individual flats can be either rented or bought outright or through shared ownership.

Shared Lives

Shared Lives (formerly called Adult Placements) means adults with disabilities live with another family or individual in their home. This is used less for people with PMLD because of the physical adaptations required. Yet, with a co-ordinated approach to finding families and getting homes adapted, this option can work well for people with PMLD.

Residential care

Residential care is the most common option available to people with PMLD. It differs from other shared housing because it is regulated and funded differently. Residential care is less flexible than other options as the housing and support come from the same provider. Most people in residential care have less personal income through their benefits and this makes it less attractive to some.

There are other housing choices that enable people with PMLD to live in ordinary properties and arrange their care and support separately:

Home ownership

There are Income Support rules that enable disabled people “moving to a property more suited to the needs of a disabled person” to get interest paid on a mortgage (at the time of writing this guide this is up to £200,000). The interest is currently paid at 3.63% by the Department of Work and Pensions, so this option relies on getting a mortgage at this rate or being able to top up payments.

An inheritance or trust can also be used to purchase a home.

There are various ways to buy your own home:

- purchase outright
- through the Home Ownership for people with Long-term Disabilities (HOLD) programme
- through Extra Care-type schemes where some flats can be purchased

- through the Newbuild Homebuy programme
- or through re-sales of existing shared ownership properties.



Scenario 2: Mark

Mark has PMLD. His needs and behaviours mean many environments are not suitable for him because he often places himself and others in danger. After being in an assessment and treatment unit for two years, Mark was able to buy his own home through the shared ownership route. This meant that he could get a house around the corner from where his parents live and that he could look for a house that suited his physical needs and could be adapted especially for him.

Renting a home from a council or a housing association

This is called social housing and to get it you need to go on a council housing register. Housing Associations are registered landlords who can access government funding to develop ordinary adapted properties and supported housing. There is a great demand for this type of housing and a dwindling supply. The best way to enable people with PMLD to access social housing is through good partnerships, planning and commissioning between housing, health and social care.

Renting a home from a charitable or non-registered landlord

There are charitable and non-profit making landlords who develop housing for people with disabilities. They are unable to get government subsidies but do have the potential to develop more bespoke and flexible housing solutions. These landlords can be treated as 'exempt' for Housing Benefit purposes and charge higher rents to reflect the greater investment they need to make for some housing.

Renting a home from a private landlord

You can rent from private landlords or through schemes set up by Housing Associations and charities who act as intermediaries. Most housing available through the private rented market is not adapted to the needs of people with. In addition, Housing Benefit pays a capped amount to private landlords, called Local Housing Allowance (LHA), which often does not meet the rents demanded for adapted or specialist housing. The only way that this will become a significant source of housing for people with PMLD is through a planned approach by commissioners, private landlords and investors.

Family investment in housing

Some families or individuals may have access to funds to contribute towards housing. Putting money into housing could be a good way to help secure their future and spend money in a way that gives them a better life.

More families want to find their own ways to find the right housing for a relative with PMLD, and housing and social care commissioners need to facilitate this more effectively. They should enable families to come together and part- or fully-fund schemes for people with PMLD.

Families can invest in housing by:

- **buying a** property outright with capital or trust fund
- **buying a** share of a property through shared ownership
- **lending a** Housing Association the equivalent of a share of a property, called Family Funded Shared Ownership
- **buying a** property and renting it to their disabled family member
- **jointly investing** in property with other families through a shareholding company
- **building a** self-contained extension to their own property and renting it to their disabled family member.

The **guide for commissioners** has more information about how to achieve these things.

4. How do people access suitable housing?

Getting the right housing and support for people with profound and multiple learning disabilities (PMLD) requires pro-active planning with individuals. This needs to be done at an early stage in the education system and flow seamlessly through to planning in housing, health and social care in order to break the cycle of providing services in crisis situations.

Families need to be clear about what they want (and what they don't want). Sometimes social workers, housing departments and commissioners are not aware of the alternatives to residential care and, even if they are, sometimes lack the resources, knowledge or skills to make them happen.

The best way to ensure that a person with PMLD gets what they want is for families to educate themselves on what it is possible to achieve in terms of housing and support, and what would work best for their family member. List what is essential, what cannot be

compromised, and what is desirable but could be compromised on to keep you focused on getting the right solution.

Financial pressures mean social services can sometimes be unwilling to do anything more than what is required by law. Relevant law and policy is explained in the next section. However, a crucial thing will be showing that 'housing' is a need for the person, and why a particular sort of housing may be a need. To get social services to consider housing options for people with PMLD, families may need to be clear that they are not able to care for the person at home. They may also need to explain carefully why a particular sort of housing is needed. For example, someone with PMLD may need to live in their own place with support because of their complex physical and healthcare needs. Families may need support to make these sorts of cases. Carers' groups or advocacy services could be a good place for families to get this support. See the section **If the person can't access the services they need**, later in this guide, for more information about how families might challenge or campaign when the person isn't getting the right housing.

It is also crucial that those people without family can get housing which truly meets

their needs. An independent Mental Capacity Advocate (IMCA) must be involved in decisions about accommodation for an adult who lacks capacity, when they don't have family or friends to speak up for them.

It should not be the case, but the reality is that the best housing and care solutions for people with PMLD often come about when families are in the driving seat and making it happen.

There are two complementary and ideal pathways. The housing and care commissioners' pathway is in the **guide for commissioners**, and the individual pathway is outlined below.

Individual pathway to housing

Age 13

Social services, housing and education should regularly share information about housing, care, funding, rights and choices from the age of 13, throughout the transition planning process.

Age 16

The person can go on the council housing register.

From age 16

Plan housing options with the transition review. Identify the following things for future planning and review them at least once a year:

- approximately when housing will be needed
- preferred areas to live
- adaptations and/or space required
- type of housing preferred - adapting the family home, independent property, extra care housing model or shared housing
- outline of care needs
- potential housemates.

When the person is ready to move from the family home:

- family receives specialist advice about housing and care options that take into account their circumstances
- identify ideal and acceptable housing preferences with family
- identify resource allocation and or mechanism for care
- identify whether family or individual has resources for funding housing
- involve an occupational therapist (OT) in identifying physical needs for the property.

Local people and families to come together to plan services:

- individuals are supported to identify compatible housemates
- families are facilitated to come together and plan joint housing solutions
- families are facilitated to come together to explore joined-up ways of supporting family members.

If it is established that the individual does not have mental capacity to contract for housing, the process is:

- a 'best interests' meeting is held
- if it is commonly agreed it is in the individual's best interests to contract for housing, agree with the landlord that no signature will be required to secure the tenancy
- if there is a pre-existing attorney with the authority to do so, that person should sign the tenancy
- if the decision-maker's conclusion that the tenancy is in the individual's best interests is not commonly held, or the landlord insists on a signed tenancy, you can seek the authority of the Court of Protection to make the tenancy valid
- in the case of purchasing a home with a mortgage, once it is established that it is in the person's best interest, you can seek the authority of the Court of Protection to contract for the mortgage on their behalf.

Law and policy which can help

It is useful to know about policy and laws that help people with PMLD to assert their rights to housing and care. Local authorities are currently making financial cutbacks and sometimes make decisions about providing, withdrawing or funding services that are not lawful. Usually as a last resort, people with disabilities and their families are using the law to challenge these decisions or inaction on the part of a local authority.

Community Care Act 1990

Under the Community Care Act 1990, Community care assessments should assess housing needs. Social services have a duty to meet all eligible needs. So if housing has been identified as an eligible need, then social services must ensure it is met. However the actual legislation to provide housing to meet the assessed need comes under the National Assistance Act 1948. Getting housing identified as an eligible need is likely to involve families being clear that they cannot support the person at home. If the person requires a particular sort of housing to meet their needs, then there will only be a duty to provide this if it has been identified as an eligible need. Families may have to push for this.

Right to housing and care under the National Assistance Act 1948

Social service departments have a legal obligation to make sure people with disabilities are housed if they do not have anywhere else to stay. This is different from the Homeless Persons Act. The National Assistance Act 1948, says social services must assess the needs of any person who contacts them who appears to be in “need of care and attention” because of age, illness, disability or other circumstances.

Chronically Sick and Disabled Persons Act (CSDPA) 1970 also provides a duty to provide adaptations to the home where this is identified as an eligible community care need on assessment. Where such a need has been identified, social services (children’s or adults team) should refer this to the housing authority who will then consider whether a Disabled Facilities Grant (DFG) should be made. However, if the housing authority refuses or is unable to approve the grant (for example because the works in question do not meet the criteria of the scheme) this does not necessarily mean you won’t get what you need. Socials services still have a duty to meet an assessed need under section 2 of the CSDPA.

Rights to housing

People with PMLD have the same rights as everybody else to be protected by laws covering housing and care. The only difference is they often need extra help to communicate and enable others to understand the choices they are making or which would be in their best interest.

Rights to social housing

People with PMLD have a right to apply for housing through the housing register. It will depend on their circumstances as to whether they have a priority or a right to actually get social housing. Most councils operate a choice-based lettings scheme where applicants to the housing register are given a banding according to their priority and can then bid for available properties. It is important that the person is given the correct banding that reflects the urgency of their need. Families could ask the local authority what their policy on social housing for people with PMLD is. Recent guidance accompanying the Localism Act highlights that people with a learning disability are a priority group, so local policies should reflect this.

It is important that people get housing which meets their needs. People with the most complex needs might need a home with

lots of space to meet their physical, health, communication and behaviour needs. They may also need a detached property or one with a driveway. There are often few social housing options which would meet these needs, so social housing may not always be appropriate.

Localism Act 2011

The government brought in new powers for communities that may be helpful in helping people with PMLD get housing.

The ‘community right to challenge’ gives local community groups, parish councils and local authority employees the right to express an interest in taking over existing council services. The local authority must consider and respond to this challenge and run a procurement exercise where the challenging organisation can bid.

The ‘community right to buy’ assets of community value will include the right for community groups to buy council services that come up for sale or change of ownership. The ‘community right to build’ gives groups of local people the power to deliver the development that their local community wants, with minimal bureaucracy.

The Homelessness Act 2002

Those classed as being in ‘priority need’ and

who are homeless through no fault of their own may have a legal right to be housed by the council. Being homeless might mean that it is no longer acceptable for a person to live in their current home. In the case of people with PMLD, this might mean their family can no longer care for them.

If the housing department feels it cannot meet the person’s specific care and support needs, they might work with social services to look at residential care or supported housing.

In theory, a council is only obliged to re-house on grounds of homelessness if they believe the person has the legal capacity to make the application and understand the offer of accommodation. However, in practice many local authorities are prepared to help people with disabilities and focus on their vulnerability in order to use their duty to rehouse.

Welfare rights and housing costs

Most people with PMLD will have the right to welfare benefits to pay housing costs if they are receiving Income Support or have a low income.

Housing Benefit helps people on a low income pay the rent in supported housing, council and housing association rented properties. Local Housing Allowance can be claimed for housing rented from private or charitable landlords and is set at a fixed rate according to the area.

If someone has very specific housing requirements and needs housing that costs more than the standard housing benefit rate, they may be able to get access to higher housing benefit payments via a route called ‘exempt accommodation’. However, at the moment there is no entitlement to this higher rate. The regulations around exempt accommodation are currently under government review following recognition that this route to housing for people with very specific needs is not working properly.

There is also the option for someone to have a mortgage (see earlier section on home ownership). Support for mortgage interest can be claimed to pay up to 3.63% of interest on a mortgage of up to £200,000 taken out to buy housing more suited to the needs of the disabled person.

If the cost of the housing cannot be met by Housing Benefit or Support for Mortgage Interest, a local authority or health commissioner can make extra payments to meet housing costs or make a grant towards the cost of the property so that the rent is lower. Some commissioners do not want to pay housing costs but many understand that it can be more cost effective and give better outcomes if they do.

Equality Act 2010 and Human Rights Act 1998

As well as equality legislation to protect all people with disabilities from being discriminated against, the Human Rights Act 1998 gives a number of human rights about housing and property:

- the right to own, and enjoy the ownership of, property
- the right to respect for private life
- the right to respect for family life
- the right to respect for your home.

People also have the right not to be discriminated against in respect of any of these rights. If a public authority does discriminate against someone by interfering with these rights, they may be able to bring a claim in the courts.

(Note: the ‘right to own property’ is about a right in principle. It does not entitle you to a property.)

The United Nations convention on the Rights of People with Disabilities

Governments should ensure disabled people have the right to choose where they live and who they live with. No disabled person should be unlawfully forced into a particular living arrangement (for example, be forced to live in a

care home against their will). Disabled people should have access to a wide range of support services (at home and in the community) including personal assistance to prevent isolation and support inclusion. Disabled people should be able to access the same community services as everyone else.

The Mental Capacity Act 2005

Following the provisions of the Mental Capacity Act will ensure people with PMLD who do not have the mental capacity to make some or all decisions, are still involved in choices about housing and care. It will also ensure their families are consulted.

Valuing People Now and Putting People First

The Government’s Valuing People Now learning disability strategy laid out a clear direction in housing choice and person-centred approaches for people with learning disabilities. In addition, its Putting People First strategy made clear that personalisation is the way forward in social care.

If the person cannot access the services they need

It is often difficult to get commissioners, housing departments and families to work together to plan housing and education for people with PMLD, and systems may only

respond to crisis situations. This often means that a person with PMLD ends up in the nearest residential care home with a vacancy.



Scenario 2: Gregory

Gregory has PMLD and lives with his mother, Jan, who cares for him 24 hours a day, except when they get some occasional respite. Jan found out about HOLD, a scheme to help people with disabilities buy their own homes. Together with Gregory’s social worker, she went through a process of planning for Gregory to move into his own home. However, Gregory was in the process of buying his home when the rules for paying mortgage interest changed and the lender withdrew his mortgage offer. It meant he has been unable to buy his own home and there are no local alternative housing solutions. Jan does not know how much longer she can go on caring for Gregory, but is reluctant to allow him to be placed in residential care where he will have no control over where he lives and the people who care for him.

If the person with PMLD who you support, or other people with PMLD in your area are not getting the housing they need, you may want to challenge or campaign.

Your local Learning Disability Partnership Board (LDPB) can be a good place to get advice or support and link up with other people to campaign. Many now have a PMLD champion or PMLD sub-group. Carers' groups, local Mencap groups or advocacy organisations can also be good places to bring people together to support each other and campaign.

Challenging

Sometimes you may just be trying to change things for the person with PMLD who you support rather than trying to get wider change.

Some tips:

- Use the information in this guide, including what 'good' looks like, legal rights and policy information, to support your challenge.
- If the person's needs are not being met, say so in a letter to the lead person at social services or the Clinical Commissioning Group (CCG). Let them know you will campaign publically against their decision if they do not listen to what you have to say.
- Get your local councillor or MP involved. You could ask them to write a letter of support.
- If you are not listened to, you might want to make a complaint or seek legal advice (see below)
- If there are other people with PMLD in the area facing similar issues you may want to get together to campaign publically!

Campaigning

If a particular issue is affecting more than one person with PMLD in your area, you may want to work with others to raise awareness about this and campaign publically for change. An example of an issue that many local areas have successfully campaigned against is the lack of appropriate changing facilities for people with PMLD. Thanks to campaigning, many local areas now have Changing Places toilets.

Some tips:

- Organise a campaign for people in your area to send an email or letter to their councillors.
- Launch a petition explaining what you are campaigning for.
- Hold a public meeting to tell people about the campaign and how they can get involved. You could invite a local newspaper or radio station along to cover the story.
- Organise a rally by inviting members of the public to a significant place, such as a town hall, to publicise the issue. Again, your local media might want to cover this.
- Gathering real stories and using photos and film can be very powerful. Social media can be a useful tool to share these.
- Don't forget to plan your campaign!

To help you challenge and campaign, see:

The Challenging Behaviour Foundation information sheet **Ten Top Tips**, by **Luke Clements**, which sets out the legal rights to community care services, has a template letter to follow if you want to challenge a community care decision. See <http://www.thecbf.org.uk>

Mencap's **Know your rights local campaigns guide** (this is specifically about cuts, but it has some useful general information about campaigning). See www.mencap.org.uk/node/14506

The **KnowHow NonProfit** website, which is part of the National Council for Voluntary Organisations, has lots of useful ideas about campaigning, including how to plan a campaign. See <http://knowhownonprofit.org/campaigns/campaigning/planning-and-carrying-out-campaigns/planning/planning>

Complaints or legal action

Some people may choose to go down the complaints or legal route if their challenging or campaigning is not successful.

Complaints

See our factsheet about making a complaint. It includes some specific information about making complaints in relation to each of the topics in the *Raising our Sights* how-to guides. See <http://www.mencap.org.uk/raisingoursights/complaintsfactsheet>

Legal action

Getting legal advice can be helpful. It is useful to do this sooner rather than later as some cases, such those involving the Human Rights Act or the Equality Act, have time limits on them. It doesn't necessarily need to cost you anything because you might be entitled to legal aid or be able to get a law firm to take on your case for free. For further information, or to find a solicitor, contact the Disability Law Service on 020 7791 9800 or at advice@dls.org.uk

4. Detailed case study

Cinnamon

Cinny is 41 years old and lives in Newbury, Berkshire, where she rents her own two-bedroom flat from a housing association. She lived with her mother, Joan, until she was 30 when they decided Cinny needed more independence and she applied for a home through the council.

Cinny would be described as having PMLD so needs help to carry out all daily living tasks. Her family discovered that she could indicate some of her wishes by blinking her eyes for 'yes' and 'no', and this form of communication is used to maximise the control Cinny has over her life. Getting her own home was not the normal way to do things so it was not a straightforward or easy process, but it has given Cinny and her family the life they have chosen.

Getting a place to live

The planning started when Cinny's day centre sent out a questionnaire to everyone about planning for the future, which asked if and when they planned to move from their family home. Joan filled it out with Cinny, saying that moving

into her own home could be a positive step for Cinny to take now, as she was showing that she wanted more independence from her family.

Kevin Lewis, the commissioner in Berkshire at the time, recalls the work his team did more than 10 years ago that meant Cinny and other people in her situation could get their own homes. He says the team was particularly strong and all had the right values and commitment but, most importantly, were prepared to go the extra mile to make sure that change actually happened. Kevin feels that it would be much harder to make a difference if you were the lone voice of change, as can be the case in many local authorities.

One member of Kevin's team had a talent for engaging with people outside health and social care. He knew how to relate to housing providers and funders that had no experience of disability, and was able to get them to see the commercial sense of providing housing, regardless of any moral duty. The commissioning team formed strong partnerships with housing providers in Berkshire and surrounding areas, and

most developments formed as a result of this partnership. They were able to jointly pull apart complex issues and see the solutions at a time when it was assumed that people with PMLD could only live in residential care. The commissioning team in Berkshire felt it was important to start from the assumption that people should be treated the same as everyone else and this included their rights to housing. This led them to explore home ownership and other ordinary housing solutions for people with PMLD.

They regularly asked people with learning disabilities and their families what they wanted in the future so they could plan more accurately, and worked with families to get them thinking about alternatives to residential care. They also got people to apply to the housing register and made it part of the social worker's role to help individuals and families fill out the form. Cinny was supported to apply for housing with the council housing department by her mother and social worker. Unusually, six weeks later, she was offered a flat. The flat was fully adapted and Cinny applied for a Disabled Facilities Grant for hoists.



Getting support

Cinny has care and support for 24 hours a day from Dimensions, a national care provider. It took some time to get the support package set up and working well for Cinny. This was partly due to Cinny and the provider getting used to each other, and partly because the provider was not used to supporting people in their own homes and was therefore trying to apply standard care home practice inappropriately.

Cinny has had a high quality but sometimes changing team of support workers. They all have a strong sense that they are supporting Cinny to lead an ordinary life. Visitors to Cinny's home can see her personality stamped all over it and get a strong sense of who she is. Most of her support team have mastered the art of giving just enough support to enable her to be in control of her home and environment. Cinny is supported to communicate her needs in different ways, including through the use of assistive technology.

Her mother feels these things have been important in making sure Cinny gets the right support:

- recruitment. Providers need to

understand communication with non-verbal people is vital

- positive attitude, listening and watching body language participation
- staff able to understand requests and carry out tasks given
- a good memory and attention to detail. Cinny always remembers things people have said (and didn't agreed with) by showing her frustration in many different ways
- family involvement is really important and should be agreed on at the start. Fortunately, the care provider has this policy and this makes the support for Cinny much clearer all round.

What Cinny's life is like now

Cinny lives close to her family and friends and sees her mother, sister and nieces regularly. She is a talented artist and surrounds herself with her paintings in her home, and shares them with family and friends. She continues to have art lessons to build her skills in painting and handicrafts, and is also working in a recording studio using musical instruments and vocalising in microphones. Cinny and Joan spend one weekend together every month without care workers so that they

can just enjoy each other's company. Personal budgets have enabled Cinny to choose new day services and activities; where she goes, what she does and who she wants to be with. Budget cuts have affected Cinny which has meant looking at more cost-effective ways to provide staff, by reducing the overall number and sharing her support workers with other people living close by. Sometimes her support staff are moved around to provide adequate cover at all times. These changes have taken time to adjust to and, while they are not easy, Joan recognises it is necessary to do more with less money.

What made the difference for Cinny?

There are some things that will always make a difference to people's lives:

- partnership
- person-centred approaches
- strong leadership
- forward planning
- family involvement
- creativity
- resourcefulness
- a can-do attitude.



All these things were in place when Cinny needed to move from her family home, but came from the people involved and their personal attributes and commitment, rather than organisational policies. Cinny was ready to move while Joan was committed to her daughter having an ordinary life and was willing to let go and take some risks. The social worker was fantastic, person-centred and resourceful. The provider was willing to learn from Cinny and Joan about how to get it right, and the commissioning was proactive, person-centred and forward thinking.

These conditions, skills and practice do of course exist in part in many areas and with many people, as do the right organisational policies that should enable people with PMLD to get the right housing when they need it. What is rarely experienced, however, is every person and organisation involved in getting housing for people with PMLD in any one area sharing vision and commitment to achieving good results. This needs to be a priority for commissioners.

6. Film

Watch Cinny's film, which shows how she has got housing and support which meets her needs, and what the impact has been on her life.

www.mencap.org.uk/raisingoursights

7. Frequently asked questions

Q: Isn't it too expensive to support people with profound and multiple learning disabilities in a person centred way? Don't they need to go into residential care or nursing homes?

A: There is no evidence to suggest that this is the case. Most people with profound and multiple learning disabilities need high levels of support which they would require whether they were placed in a service or had a service designed around them. A person-centred approach means that resources can be allocated to what a person actually needs more effectively.

Q: There is no adapted housing in my area so how is it going to be possible to get it for people with profound and multiple learning disabilities?

A: It is important to explore all the different housing types and options before concluding that no housing is available. It needs a proactive approach between commissioners and housing providers to plan adequately for local people with profound and multiple learning disabilities.

Q: How is it possible for people with profound and multiple learning disabilities to make choices about where and how they live?

A: Choices are made in many different ways. For people who do not communicate with words, choices are expressed by showing like or dislike of people or situations, and by those who know them well knowing what is important to the person. For example, it may be that the person expresses that being with their family or an activity is important to them so housing choices must reflect their desire to maintain those important aspects of their life. The Mental Capacity Act has guidance for procedures if anyone is expressing doubt about a person's capacity to make choices.

Q: My daughter has no verbal communication. How do I know she will be safe in her own home?

A: There is no one system or organisation that can guarantee a vulnerable person will be safe whether they live in a care home or in their own home or sharing with friends. If a person with profound and multiple learning disabilities

lives in their own home, the domiciliary care provider will be regulated by the Care Quality Commission, and the provider will have procedures in place to recruit and train their staff in a way that keeps people safe. Social Services and health commissioners have a duty of care for your daughter and should be monitoring the quality of care provided to her. So it is important to find out how these organisations work to ensure your daughter's safety.

In addition to regulation and monitoring, the best ways to ensure that your daughter is safe are to:

- make sure you are involved in recruiting staff (whether that is via a care provider or direct employment) so you have control over who supports her
- try to make sure she is living in her community where family and friends are in regular contact with her and will notice if something is not right
- take a person-centred approach to safeguarding - rather than only having general policies and procedures to keep her safe, and think about what could work for

her and what everyone around her needs to do to keep her safe

- ensure that person-centred plans relate to the staff roles so that they are clear about what they should be doing to keep your daughter safe.

Q: If a person has complex health needs, surely they can only be cared for in a residential setting staffed by highly skilled professionals?

A: There are some medical procedures that always require the support of highly skilled health professionals and this applies whether a person lives in residential care, supported housing or their own home. If an individual needs regular healthcare interventions, there is no reason why professional healthcare cannot be given in their chosen living environment. People with complex needs always require highly skilled staff to support them on a day to day basis but it is not always necessary for those staff to have a particular professional background. With the right attitude, commitment and training there are people from all walks of life who support people with profound and multiple learning disabilities well.

Q: My son would like to live with other people. How do I find people with similar interests to him to be his housemates?

A: Who you live with has a major impact on quality of life and it is important that people with profound and multiple learning disabilities are able to live with people they get on with. The current systems for getting people housing do not initially take preferred housemates into consideration. We recommend to commissioners that an important part of the process in planning housing is that they bring together individuals and families to identify potential housemates.

If this does not happen in your area, it is worth putting out a ‘housemates wanted’ note via carers groups, colleges, community learning disability teams, etc, and trying to connect with potentially suitable housemates that way.

Q: Are there housing associations that work directly with families?

A: Most housing associations work directly with councils to plan and deliver local housing. They often do not have flexible financial and planning procedures to work creatively with families. However, they are often willing to talk to families and see how they can help.

The Localism Act encourages local people and organisations to be more flexible with the planning and delivery of housing.

There are some specialist housing providers that can work with families. Please see the *Links to further information and resources* section of this guide.

Q: What if someone moves into their own house or flat and it does not work out for them?

A: The answer to this really depends on why it didn’t work out. The best way to plan getting somewhere to live is to be as person-centred as possible, thinking carefully about the individual and what is right for them so as to avoid having unnecessary moves in the future. This is especially important for someone who needs a lot of adaptations to their home as it is not so easy for them to find somewhere else to live. However, even with the best plans, things may not work out so it would be important in this case to get a reassessment of housing and care needs, and actively plan alongside commissioners for another move. Priority for alternative housing will depend on the individual situation.

Q: We feel our daughter would like to live in a nice home in an area close to her family. What if the council offers her something we don't like?

A: Most councils now operate a choice-based lettings scheme which means that, instead of the council offering a home, people search and bid for properties they would like. This gets around the problem of not accepting an unsuitable property. However, there is little choice of housing in the social rented sector in many areas, and it is only those with greatest priority who are eligible for this housing.

It might be better to explore alternative housing options, such as shared ownership or family-led options (as described in this guide) so you have more choice and control over where your daughter lives.

Q: If my son does not take the opportunity to move into housing at transition stage, is this something that can be reviewed at a later date?

A: Yes. If you are both happy with the situation at home, your son can move when it works best for you all. Often people with profound and multiple learning disabilities (PMLD) get housing in crisis situations and it is better to plan ahead

and know what you want. Commissioners should ask people with PMLD and their families about their housing needs at least once a year, so they can include this in their long term local plans.

Q: I've heard some charities and organisations have created bonds and other ways for people to privately invest in order to help people with a learning disability get housing. Is this something that could help my relative?

A: This might be something that could help. It can certainly help make more properties available, but it will still rely on people with a learning disability paying a certain level of rent (usually through housing benefit) that allows the scheme to pay interest to investors.

For those with the most profound needs who require extensive adaptation or who wish to live on their own, the level of the local housing allowance they receive may not be enough to then cover the interest which needs to be paid to the investor. This is something that can be a particular issue at the moment when there are problems getting a higher rate of housing benefit through the exempt accommodation route (as current government rules have made this route unreliable).

It will depend on the individual situation, whether or not this route could help someone with PMLD get housing. For more information about such schemes see

www.housingandsupport.org.uk/investing-in-ordinary-lives. Golden Lane Housing has recently launched a bond scheme specifically to help people with a learning disability get housing. For more information see www.glh.org.uk

8. Share good practice!

We know there is already good practice out there and some examples are referred to in these *Raising our Sights* how-to guides. But we would like to hear of more examples and share them so other local areas are inspired to develop good support and services for people with PMLD too.

Please tell us about any good practice in your local area relating to support or services for people with PMLD:

Email pmlidnetwork@mencap.org.uk
Call 020 7696 5549



The Lambeth PMLD project

This project aimed to show what life was like for people with PMLD in Lambeth, and use the information to better plan to meet their needs. It was initiated by family carers of people with PMLD on the Lambeth learning disability partnership board and run in partnership with Lambeth Council, NHS Lambeth, 'I Count' Register Services, National Mencap and Lambeth Mencap.

The project identified people with PMLD on the learning disability register using criteria developed from the PMLD Network definition. Information was also collected through surveys and interviews with families and support staff.

Priority areas for change were identified and, two years on, there is an active PMLD sub-group committed to take these forward. The focus is currently on developing meaningful activities for people with PMLD in Lambeth. There is a case study and film of Lambeth's work

on meaningful activities work in the *What people do in the day* guide.

For more information about the Lambeth PMLD project see:

www.mencap.org.uk/Lambethpmlid

9. Links to further information and resources

National organisations that can support with family led housing solutions:

Advance Housing www.advanceuk.org

Golden Lane Housing www.glh.org.uk

Housing and Support Alliance operates a free advice service for people with learning disabilities, families and advocates.

Telephone: 0845 456 1497

Email: enquiries@housingandsupport.org.uk

<http://www.housingandsupport.org.uk>

Information about housing options, support, assistive technology, rights, capacity and funding can be found at:

www.housingandsupport.org.uk/resources-and-library

Acknowledgements

Thank you to Alicia Woods, chief executive, Housing and Support Alliance, who was the lead author for this guide. Thanks also go to all those who read and commented on the guide. Their input has been invaluable.