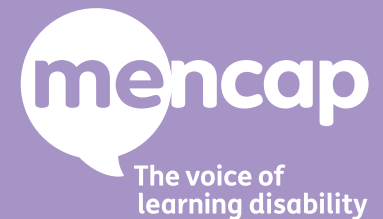




How-to guide 10 wheelchairs

For people with profound and multiple learning disabilities

**Raising
our Sights**



Raising our Sights guide to wheelchairs

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 make sure 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 wheelchairs 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

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

1. What Raising our Sights says about wheelchairs

There are four recommendations:

Recommendation 14.

The Department of Health should reform the wheelchair service to address the problems identified in 2006

Recommendation 15.

Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person

Recommendation 16.

People with PMLD who have used powered wheelchairs (eg. 'smart' wheelchairs) at home or at school during childhood should have the option to continue to have them provided in adult life, where it sustains or enhances their quality of life

Recommendation 17.

Other people with PMLD should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life

Over the last 10 years, there have been many reviews and a lot of guidance and policy covering the provision of wheelchairs and the wider context of health and social care.

This guide is specifically aimed at those who support people with profound and multiple learning disabilities (PMLD) who need more complex seating. It will help local areas implement the *Raising our Sights* recommendations and understand and meet the needs of people with PMLD.

This guide focuses on what a good wheelchair service looks like and what needs to be in place to ensure people with PMLD have suitable wheelchairs.

For people with PMLD, the fundamental truth is that a wheelchair that fully meets their needs is based on a good clinical prescription.

Before expanding on this, it is worth looking at some key facts:

- **The number** of people with PMLD is currently very small at approximately 16,000 in 52 million. However, this is increasing because better medical and social care means more people are surviving into adult life with increasingly complex needs.
- **A number** of people with PMLD who need wheelchairs will have very complex seating or postural needs, and/or will benefit from smart technologies as an integral part of their chair.
- **Unlike most** people who use wheelchairs, people with PMLD are predominantly young and under 60.
- **Good seating** significantly reduces the risk of physical deterioration and secondary complications. For example, the total cost of pressure ulcers alone to the NHS is 4.1% of its gross annual expenditure.

- **The UK's** signature to the UN Convention on the Rights of Persons with Disabilities obliges us to work towards 'achieving progressively the full realisation of the rights of these people'.

2. What does ‘good’ look like?

At the core of the best wheelchairs is a **good clinical prescription.**

A wheelchair is often the most important piece of equipment a person has. People with PMLD cannot always speak up for themselves, but others who rely on wheelchairs are able to drive this message home:

“My wheelchair is my life – without it I would not have a life.”

Best Practice Guidance from Care Services Improvement Partnership (2006), Out and About.

This quote and the title of a report by Whiz Kidz, *My wheelchair is my shoes*, show the importance of wheelchairs as part of inclusion and normality. This is reflected in the content, conclusions and recommendations of these and other publications that are trying to drive improvements in wheelchair services.

See the *Links to further information and resources* section at the end of this guide.

Within pockets of very good practice, it is

possible to identify patterns that create success. A number of case studies show that the following are critical to improving local wheelchair services:

- better data collection
- good communication
- the right mix of expertise.



Scenarios 1 and 2

In Bury and Rochdale, waiting times for children’s wheelchairs were 40 weeks. These were reduced by half after: a number of improvements were made to data collection; reasons for non-attendance at appointments were investigated and addressed; and families in particular were given more support.

In South London they invested in a specialised seating centre for complex seating. The outcomes include improved seating and postural management that have improved the health of people, for example better digestion, breathing and fewer pressure problems – all very pertinent to the people represented in *Raising our Sights*.

Good wheelchair assessments

For people who can walk but struggle over long distances or uneven surfaces, their wheelchair is primarily a means of transport for getting them out and about in the community, in a safe and efficient manner. They can transfer into and out of their chairs with minimal assistance and transfer to ordinary seating indoors. A **basic wheelchair** with some minor modifications may be all that they need.

Other people may have problems maintaining their posture and head control. Some may have problems with spasticity and/or muscle shortening. They may have leg length discrepancies, joint dislocation and limitation in the range of movement – particularly in their spine, hips and knees. Their needs are more complex and the wheelchair will probably be the person's main means of seating, as part of their **24-hour Postural Management Programme**. They are dependent on it for their mobility, comfort, safety and ability to actively enjoy and participate in their daily life.

A good wheelchair will depend on a very thorough assessment of their clinical, lifestyle and carers' needs. The seating prescribed may be modular. There are many makes and models of modular seats that can be modified to take into account changes to a person's shape and size, and postural deformities. The wheelchair seating therapist should advise when and

where this type of chair is appropriate. These modular seating systems can be fitted to a variety of wheelchair bases according to what the person and their carers need.

If a person's complex postural and seating needs cannot be fully met by a modular seating system, they will need **customised seating** that is fully supportive and made to measure and that fits the individual closely. This type of seating should improve their comfort and where practical enhance their posture, minimising the progression of contractures and deformity. Having their posture supported and improved should also ensure the person's safety and enable them to maximise their functional ability.

A **'power chair'** uses a motor to move. A 'power chair', adapted with **'smart' technology**, has extra electronic features that might be appropriate for people with profound and multiple learning disabilities (PMLD). For example, sitting-to-standing chairs, chairs that run on track systems or have stop sensors, pre-programmed chairs to run along a specific path or chairs that allow people to be at different heights or angles. These features can open up a number of opportunities for people with PMLD in terms of the things they are able to experience and do in their wheelchairs.

Sometimes the technology may be controlled by someone else or pre-programmed. Where

there is a control switch that the person with PMLD can be supported to use (for example with their support worker's hand over theirs), this can open up a real learning opportunity for the person. It can help them over time to make a connection between the switch and the movement. There are more examples of how a smart wheelchair can support a person's independence and development in an article by Richard C Simpson in the *Journal of Rehabilitation, Research and Development* (see the links to more information and resources section).

Using a power chair (with or without smart technology) can be difficult in some environments – particularly when someone has been able to use the chair in larger spaces offered by school for example. This can be made worse by the need for a larger chair in adulthood. Serious consideration should be given to space as part of the assessment.

If a person qualifies for a power chair they are also allowed a manual chair. Both chairs must meet the needs of the person.

A power chair may help if a carer is unable to physically push the person in a manual chair, and would be needed to make sure they can get out and about.

As explained above, a power chair with 'smart' technology can give an individual

more autonomy and control, and may be one of the ways they could enjoy the feeling of independent movement – up and down, round and round or just a jolt forward – whatever is appropriate and meaningful to them. It could also improve communication skills, and support learning about cause and effect. All these outcomes could be part of maximising the wellbeing of the person.

The reality is that people aren't getting smart chairs. Many people do not meet the criteria for getting smart chairs because the criteria often doesn't consider the achievements and potential of people with PMLD. However, it could be argued that any blanket ban on smart chairs for people with PMLD ignores Article 8 of the Human Rights Act. People have a right to a private and family life. They have a right to personal development and independent movement as far as possible. For more information about challenging or campaigning see the 'If people cannot get a suitable wheelchair' section.

Case study

There is a useful example of how investment in a high-specification wheelchair can reduce health and social care costs, and improve independence and wellbeing on page 11 of the Department of Health's report *Out and about* (see the *Links to more information and resources* section later on).

The case study isn't about a person with PMLD, but the principles are exactly the same and need to be understood: a cheaper wheelchair that doesn't fully meet the person's health and social care needs is likely to have much greater financial and human costs in the long run.

The *Raising our Sights* how-to guide on commissioning services for people with PMLD has more information about how to achieve these things.

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

- **A good clinical prescription**

- **Access to highly specialised wheelchair services.** For people who need complex seating solutions these services should include:

- training in 24-hour postural management for families and support staff of people with PMLD
- complete multidisciplinary teams in wheelchair assessment, provision and maintenance who work closely together.

A large health authority may have its own highly specialised wheelchair service. Smaller ones may group together and run a service together. Or there may be a specialised wheelchair service in a different area, ideally not too far away, that people can access.

- **Services that recognise everyone's skill and potential.** Services should respect small but significant ways in which people are able to: make choices; take part in the world; achieve new learning and skills; and be independent – despite the need for someone to accompany them. This is particularly important with

regard to access to electrically-powered chairs or higher specification manual chairs that can open up new opportunities for people.

- **Respect for human rights** when delivering services. Human rights are a central pillar in protecting everyone and supporting us to build a society that values everyone. Good seating saves lives, optimises health, promotes dignity and respect, helps people mix with others and gives people access to opportunities for social and personal development.

- **Services that are actively person-centred and take a holistic approach.** The service should work around the needs of the individual, rather than expecting the person to 'slot in' to the service. In doing this it should consider all the person's needs: health, communication and wellbeing. It should expect other services and professionals involved to work in this way too. Commissioners should make sure wheelchair services for adults are sufficiently funded to meet the needs of people with complex seating needs.

- **Honesty and sensitivity.** Sometimes people

with complex needs and their families have to make difficult choices, simply because of the very nature of their needs. This can be very distressing and needs to be handled sensitively. Be prepared for open and full conversations. See the section on assessment below for more information.

- **Recognition that good wheelchairs can prevent illness and death.**

4. How can people get a suitable wheelchair?

Referral

An initial referral is usually made by the GP but sometimes by another ‘professional referrer’ or qualified person, such as an occupational therapist or physiotherapist. The guidance, at the time of writing, also says that someone who is already known to wheelchair services may self-refer.

Assessment

Good assessors will be interested in the person, how they live their life and how the wheelchair will help them every day. The assessment needs to be a conversation and medical assessment about their needs. If they have complex needs, families should expect, and assessors allow, enough time for the assessment. Sometimes this could be as long as two to three hours.

During the assessment, the person’s health and their life will be discussed and the assessor will take some vital measurements about joint range and overall body condition. There should be proper equipment for the assessment such as a ceiling hoist and physiotherapy plinth. For some measurements the person will probably need to be out of their chair and on the plinth. Sometimes these conversations can be difficult.

There may be tensions between different outcomes and these can make the assessment, prescription and provision more complex. So it is important that everyone is honest with each other.

The team doing the assessment can vary but the core team should be:

- a family member and a familiar, skilled care giver
- a lead assessor who is qualified and experienced in postural care, neurodisability and rehabilitation
- a technician who is qualified in rehabilitation.

Some assessments might also require a clinical scientist, speech and language therapist and an electronics engineer. For example, for a power chair or smart chair, it will be important to get any switches and electronics in the right place, and ensure they work together in an integrated way.

It is important to think about these things and plan for the assessment. The wheelchair is a major piece of equipment that will have long-term effects on the person’s life. It is also a major cost whether supplied by the NHS or privately funded.

Think about outcomes – what do you want the wheelchair to achieve? For example, do you want the person to be more comfortable, take part in the things they want to do, or do you want to stop their head from feeling heavy?

Involve the person in planning and preparing for the assessment:

- Jot down a few notes about the person’s health such as ‘I get chesty’ or ‘I get sores on my toes’ (you could use a summary of the person’s health action plan) and any equipment they use. This is the person’s ‘health profile’.
- Make a few notes about what the person does on a typical day, some things they like to do occasionally and things they want to do but cannot do at the moment. This is the person’s ‘lifestyle profile’.
- Bring some photographs of the person doing things (perhaps in their current chair)
- Try to find out what could be available – different types of wheelchair, moulded seating, etc.

Making decisions

Families sometimes have to make difficult choices because of the very nature of the person's needs. These compromises are not always about money but can arise because people with profound and multiple learning disabilities (PMLD) might have different and conflicting outcomes.

For example, desired outcomes might include:

- be comfortable for the person
- help their ability and independence
- minimise complications - including secondary/ future complications
- support care giving
- the wheelchair as part of a whole lifestyle.

One example of conflict might be comfort versus independence. A wheelchair may need to be tilted back for periods of time and this might inhibit the use of a switch. Or it could be tempting to try to correct a posture to regain a skill when the person is most comfortable in a chair that accommodates their current posture. Assessors often have to weigh a carer's need for a lighter chair against the person's need for a robust chair because of strong spasms. Carers themselves frequently develop problems due to physical handling, even where risk has been

reduced as much as possible. This can mean a future cost to the NHS and to the carer. It may be possible to solve this by providing a rigid frame or, if possible, reducing the size of the frame, repositioning the pushing handles or considering having a power pack to help.



Scenario 3: Independence versus prevention of secondary and or future complications

James is learning to tolerate a headrest for longer. He is good at giving eye contact to speakers. And he's used to looking around to fix his eyes on whoever is talking or whatever he finds interesting. This supports his ability to understand and communicate with the world. However, his neck is becoming progressively out of line. Over time it could interfere with the way he swallows.

These are really difficult issues to resolve and they illustrate why both clinicians and carers need to have an open and honest dialogue to help them agree a compromise when there are conflicting outcomes.

You may find it helpful to ask some of these things during the assessment:

- **How long** should it take to get the wheelchair?
- **Will it** fit in the family member's or carer's vehicle?
- **Can the** person travel in their chair in the vehicle?
- **How can** we prevent the person being too hot in their chair or getting sores?
- **What are** the options if the person likes to communicate using their whole body but gets sores where the belts are or gets into a bad position in their chair?
- **Does the** person need a harness?
- **What is** the best sort of head support that does not get in the way when the person looks around?
- **How can** we keep the person's feet on the footplates?
- **Can there** be extra sets of wheelchair covers to allow for washing?
- **Who is** the person to contact about breakdowns and repairs and who pays for these things?
- **Will the** wheelchair transport oxygen, medicines, peg feed or other equipment?

- **Will the** person's communication aid/switch or a tray fit on?
- **What size** wheels are best to meet the person's lifestyle?
- **Can the** suspension be improved so the person's back does not hurt when their wheelchair goes over a bump?
- **Can the** person choose the colour of the chair?



Scenario 4: Make sure there is a clear maintenance a repair contract in place.

Any modifications made to a wheelchair, even if they are clinically needed, may affect the manufacturer's warranty.

Jo's Dad explained:

“We had an active lifestyle. The chair our child was being offered was heavy, bulky and ugly. We got a private assessment for a lightweight super chair and paid a deposit of £2,000. Then the company supplying the chair went bust. By now our son was desperate for a new chair. We found another supplier but we had to agree to accept the chair when it arrived even if it was wrong. It cost another £5,000. The chair was very wrong but our son had to use it until the NHS chair arrived. When it broke it cost £200 for the call out. The money was bad enough – but the damage to our son's health.... I'm still very, very angry.”

After the assessment

The assessor should write a report setting out what they found and what the person needs. Copies of this should be sent to the person and appointed carer, their GP and whoever is funding the chair. When funding is agreed, a prescription can be written for the chair.

The number of appointments needed depends on the seating the person requires. Some wheelchairs can be issued right away. Some will take another appointment for fitting, and people with complex needs may need at least three more appointments before the wheelchair is issued.

These appointments could include the following:

- **CASTING.** When a person needs a moulded seating system they will have a cast taken of their body. The casting appointment may take up to two hours. It is really important that the cast is accurate. Measurements might need to be checked again, the person might need time to relax and reduce spasms, and the posture will need to be arranged so that the fit is comfortable. It is better for the person and the service if this is done correctly first time round.
- **FITTING.** The cast will be used to make a moulded seat. Once the mould is made, there is more detailed work to get the mould right. Some people assume there is only one type

of moulded seat. There are different types of mould to meet different needs. Fitting can take three or four hours.

- **Issue.** This is for fine tuning and information about how to use the chair. This can take up to two hours.

Law and policy that can help

The main legislation applied to the provision of wheelchairs includes:

- **the National Health Services Act 1977 and the General Medical Services Regulation 1992** – wheelchairs for permanent use are on a list of items of equipment that must be prescribed
- **the Carers (Representation and Services Act) 1995** – carers are entitled to an assessment and their needs must taken into account
- **the Human Rights Act**, articles 2, 3 and 8 – public authorities such as local councils and health authorities must comply with basic human rights:
 - Article 2, the right to life – failure to provide an appropriate wheelchair may threaten life.
 - Article 3 protects against inhuman or degrading treatment – dignity and respect.
 - Article 8, the right to a private and family life – people must be allowed the means to have relationships with who they chose and the opportunity for personal development.

Mental Capacity Act (2005) and Deprivation of Liberty Safeguards – the Mental Capacity Act says people must be supported to make choices. If they lack the capacity, decisions should be made in a person's best interests and family should be consulted unless there is a very good reason not to involve them.

The Deprivation of Liberty Act is an addition to the Mental Capacity Act. It is relevant in that people cannot be denied the freedom of movement without good reason. As well as the provision of a wheelchair, it has implications for how straps and harnesses are used.

- **The health** service also works within current government policy, for example **Equity and Excellence: Liberating the NHS.**
- **Inquiry reports can also help** Inquiry reports, such as the Francis Inquiry into the care provided by Mid Staffordshire NHS Foundation Trust, often highlight the serious consequences of not paying attention to dignity and care. The importance of dignity and care for a person could be used when making a case for a wheelchair.

If people cannot get a suitable wheelchair

Sometimes when wheelchairs arrive, there is a problem. If the chair is unsuitable you should do the following:

- Go back to the wheelchair clinic. There may be very good reasons why a wheelchair needs further adjustment, despite extensive and good assessment.
- If problems persist, or there are ongoing difficulties during the process of getting the chair, ask to speak to or write to the manager of the wheelchair service and make notes about what has happened. Think about whether this is a complaint. You may decide you want to make a formal complaint (see below).
- Wheelchair service managers want to know as soon as possible if something is wrong. Referral or prescription errors are expensive and services want to stop this happening.
- The next step is to visit your GP or consultant and ask for a second opinion. You might need a referral to a more specialist clinic or service. There may also be other health matters that have emerged since the wheelchair assessment, like a change in medication or other therapies that could help with seating.

If this doesn't resolve things, and the person's wheelchair needs are still not being met, 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). You could 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.

As described earlier in this guide, the reality is that adults with PMLD are not getting smart wheelchairs. Power chairs and smart chairs are often used in school and childhood and become an important part of people's independence and health. However, cognition is sometimes given as a reason why they cannot be supplied to adults with PMLD. If this is happening in your local area, it might be something you want to campaign on.

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 sorts of 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 email advice@dls.org.uk

5. Detailed case study



Liam has a good sense of humour and is a much-loved member of his family. Having a good wheelchair is very important for Liam. It plays a vital role in his health, mobility, comfort, and his ability to enjoy activities and take part in daily life.

His mum says that a good wheelchair with the right seating actually helps Liam stay alive. Because his condition results in secretions building up in his chest, he needs to be carefully positioned to help his breathing and digestion – something that would be very difficult without his wheelchair.

A detailed and accurate clinical prescription is vital to get a wheelchair that properly meets the needs of a person with profound and multiple learning disabilities (PMLD). The shape of Liam's body means he needs a wheelchair with moulded seating to support his posture. His wheelchair tilts back because of difficulties he has with his back and pelvis. He has a carved foam seat which makes the wheelchair comfortable for him and protects his skin. The back of his wheelchair is a 'Linx' system which

allows air to pass through to keep him cool. It can also be altered if Liam's body changes, without necessarily needing a new mould.

Liam likes adventure and he's always enjoyed being out of doors. For this reason his family wanted him to have a wheelchair with slightly bigger wheels. These make it easier for them to push him but they also give him more comfort when crossing bumpier ground.

Liam's mum says that before a wheelchair assessment is carried out, family carers should think about aspects of the person's health that need to be protected. If the person has a health action plan, this can help identify what health needs should be addressed by the assessment.

She says it is also important to think about how the person wants to use their wheelchair and what is right for their individual needs. Powered wheelchairs are very useful for some people, such as those living in a hilly area where the extra electrical power can help them tackle inclines. But they are not necessarily useful for everyone.

Liam's friend Matt, who has significant physical disabilities, has what is called a 'smart' wheelchair. This means he can control aspects of the wheelchair using technology such as a switch. It gives Matt a lot more control over his life. Smart technology like this can make a great difference for people with PMLD. Being able to control a wheelchair by pressing a button can help the person learn about cause and effect.

It took Liam's family a very long time to get the right wheelchair prescribed for him. In the end, they got him referred to a highly specialised clinic in Oxford where they managed to get the right kind of seating that gave Liam the comfort he needed. His wheelchair not only helps him to be as healthy as possible, but also helps him take part in society.

6. Film

Watch Liam's film which shows how important it is to have a wheelchair that meets your needs.

www.mencap.org.uk/raisingoursights

7. Frequently asked questions

Q: Our daughter is an adult now and my wife and I find it increasingly difficult to push her up even slight slopes. This means she cannot do many things that she enjoys and that keep her active. Is there anything we can do?

A: Go back to the wheelchair service and ask for a reassessment of your needs. You may be able to have a wheelchair with a lighter frame or a power pack.

Q: We cannot afford to pay anything towards a wheelchair. How do I know my son is being offered the right one for him?

A: The chair a person is offered by the NHS should meet all clinical needs and legal obligations, including things like minimising future complications and taking account of carers' needs. Prescriptions should comply with the law and follow best practice guidance.

Q: What are the options for moulded seating?

A: Custom moulded seating is used when someone has very complex seating needs. As the name implies, it is seating moulded to the person's body. People who have these seats will also need 24-hour postural management and other therapeutic input to optimise posture and health.

Moulds might appear inflexible, confining and as if they are very hard plastic, so it can come as a surprise to find this is not the case.

There are three commonly used types of moulded seating:

- thermoplastics
- carved foam
- interlocking systems – Matrix, New Matrix and Lynx.

Thermoplastic seating:

- is light weight
- is low bulk
- is difficult to adjust once made – casting must be exact and no anticipated changes to posture are taken into account
- can be hot
- can be difficult to clean
- feels very rigid when it's finished.

Carved foam:

- is skillfully carved from the cast, either manually or electronically
- offers varying degrees of density which can be chosen to best meet comfort needs
- can be altered for width and minor changes
- can be hot
- can be bulky.

Interlocking systems:

- has interlocking segments (like high tech Meccano) shaped around a cast or directly around the person
- can be adjusted at fitting stage or if the body grows or posture changes, and can achieve a high degree of accuracy
- has gaps between segments for air circulation so helps with people who get hot
- is easy to clean
- like New Matrix, can allow for different stiffness and 'give'
- may be heavier than some other systems
- may need a higher level of maintenance and skill to make.



Scenario 5: The right choice of mould can make a huge difference

Jane has had a number of moulded seats but none seem to last for long.

Her brother described how after every new mould, “it’s alright for about six months but then becomes uncomfortable again”.

Jane has an all-in-one thermoplastic mould with a lightly padded cover. As this is a persistent problem, there may be other moulds that are more suitable. Many wheelchairs have a combination of moulded systems. For example, a carved foam seat for comfort and a Matrix back for accuracy and temperature control.

Q: Should I accept a voucher to get my chair?

A: Some people have found the voucher system very useful. Basically this is where the NHS offers a voucher towards the cost of a manual wheelchair. The scheme was introduced to give people greater choice. There are three choices of funding open to people via the NHS:

- **Direct Issue** – the referred individual is assessed and prescribed the wheelchair from the Approved Range of Equipment List which best meets their clinical need. This wheelchair is provided, maintained and repaired by NHS funding.
- **Partnership Voucher Scheme provision** – the referred individual chooses an alternative wheelchair which they prefer from the Approved Range of Equipment List. A voucher is issued for the cost of the wheelchair originally prescribed. Any difference in cost between that of the prescribed wheelchair and the one selected by the individual is paid for by the individual. The issued wheelchair remains the property of the wheelchair service and is maintained and repaired free of charge.
- **Independent Voucher Scheme Option** – the referred individual is able to approach approved wheelchair suppliers and choose a wheelchair from a range not normally supplied by the NHS. Once a wheelchair has been selected, approval has to be given by a

wheelchair service therapist or technician – ensuring that the chosen wheelchair meets the individual’s clinical needs. A voucher is then issued for the cost of the wheelchair originally prescribed. Any difference in cost between that of the prescribed wheelchair and the one selected by the individual is paid for by the individual. An extra amount is added for maintenance and repair costs and the wheelchair is purchased by the individual

Information taken from The East of England draft Qipp. See the Links to more information and resources section at the end of this guide

Many families accept a voucher because it means they can get a lighter, better-looking wheelchair. A general feeling that people with PMLD already face enough barriers to acceptance was put into words by one mum who said: “We didn’t want her sitting in a huge, ugly chair.... our daughter loves her chair.”

If there is a very large difference between the value of the voucher and cost of the chair of choice for someone with complex needs, it may indicate either a problem with the prescription or a problem with the prescriber or supplier.

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 more information and resources

Whizz-Kidz

A charity that aims to give disabled children the chance to lead a more independent life.

<http://www.whizz-kidz.org.uk>

Publications that are driving improvements in wheelchair services

Equity and Excellence: Liberating the NHS

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

Local innovations in wheelchair services

Department of Health. (December 2010).

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122491

This document aims to support PCTs and local wheelchair service managers in the commissioning and delivery of wheelchair and seating services, by capturing current examples of local innovations that improve quality in wheelchair commissioning and delivery.

Out and about

Wheelchairs as part of a whole systems approach to independence.

Department of Health (2006).

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139932

East of England Qipp

Health care standards for wheelchair services.

<http://www.eoecph.nhs.uk/Files/Newsletters%20and%20attachments/Publications/Wheelchair%20Project.pdf>

Policy and law

Most of the relevant legislation is summarised in *Standards for Better Health - Health Care Standards for Wheelchair Users*.

<http://www.wheelchairmanagers.nhs.uk/servicestandards.pdf>

Mental Capacity Act

Using The Mental Capacity Act – a resource for family and friends.

<http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/>

Articles and publications

Smart Wheelchairs: A Literature Review. Richard C Simpson (2005).

Journal of Rehabilitation, Research and Development.

<http://www.rehab.research.va.gov/jour/05/42/4/pdf/simpson.pdf>

Severe and Complex Neurological Disability Management of the Physical Condition.

Pauline Pope (2006).

Acknowledgements

Thank you to Helen Daly, Disability Consultant and parent carer, 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.