



Valuing people with Profound and Multiple Learning Disabilities (PMLD)

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Introduction

In November 2000 Mencap and the Foundation for People with Learning Disabilities brought together a small group from other organisations (membership list attached) with an interest and expertise in working with children and adults with profound and multiple learning disabilities and their parents and carers. The group, now known as the PMLD Network, agreed that its first task should be to provide a response to the forthcoming White Paper and work to influence its implementation.

Children and adults with PMLD are probably some of the most marginalised people within our society, have some of the highest support needs and are more reliant on services. There is a need for action at every level of service provision. For these reasons, it was hoped that the White Paper would make specific recommendations and set out targets for people with PMLD.

The PMLD Network welcomes the principles set out in the White Paper and believes that *'Valuing People'* has raised some important issues that are relevant to children and adults with PMLD. However, we feel that the range of initiatives set out in the document will only benefit these individuals in the context of greater consideration of the issues that confront both children and adults with PMLD and their parents and carers.

It is our view that *'Valuing People'* does not fully address the issues for children and adults with PMLD. This is apparent in the way that it does not:

- use consistent terminology
- identify that children and adults with PMLD are amongst the most excluded people in our society
- identify children and adults with PMLD as a priority group
- make any specific objective or sub-objective for people with PMLD
- identify family carers of children and adults with PMLD as a priority group.

In many ways it could be said that *'Valuing People'* accurately reflects the problems facing children and adults with PMLD - we don't know how to describe them and therefore we don't know how to accumulate the information we require to gain an accurate picture of their needs. We are aware that we are not doing enough and that we will need to do more. Sometimes we do not think about the issues sufficiently and make changes in services that actually further disadvantage children and adults with PMLD (Samuel & Pritchard 2001).

We therefore feel that there is a great deal of work to be done to support and influence the implementation of the White Paper and will be setting out what we see as the critical issues for children and adults with PMLD in more detail in this paper.

Principles

We believe that if we are to take effective action on behalf of children and adults with PMLD there needs to be agreement about the principles we have set out below:

- **Vision:** we need to understand that whilst the overall vision is the same as for their more able peer group, the detail for children and adults with PMLD is often different. Children and adults with PMLD have specific needs that call for specific initiatives. All too often, their needs are lost within the wider agenda. This is why, at this stage, it is important to identify them as a group and focus on their additional needs with greater clarity.
- **Values:** to want to take action we need to believe that all people have value. Many parents and carers of children and adults with PMLD say that their sons and daughters are not valued and that their contribution to society is not properly acknowledged. Judgements are made about the meaning and quality of their lives. We know that children and adults with PMLD may experience the world in a different way, but also that their lives may be enriched by the things that we all share: for example, the company of friends and family, music or the taste of food. In turn, they enrich the lives of others. We need to promote the positive contribution of children and adults with PMLD.
- **Visibility:** Many people in our society simply do not know that children and adults with PMLD exist. Others have failed to understand their needs in a coherent way and have not planned for the kind of services that meet their needs. We need to make them visible.
- **Rights:** It seems necessary to state that children and adults with PMLD have the same rights as anyone else. It is necessary to reiterate this because by failing to translate those rights into actions that directly improve the quality of their lives, we actually deny those rights. We need to campaign for the rights of children and adults with PMLD.
- **Representation:** The advocacy movement has done much to enable people with a learning disability in general, to take their rightful place in society, but people with PMLD have had little part of this. We need to address the issue of meaningful representation.

Taking action

'Valuing People' has touched upon some important issues that could be relevant to people with PMLD, including a range of initiatives which could substantially benefit people with PMLD if the work is done to influence and support their implementation. However, if any real impact is to be made on the lives of children and adults with PMLD, a number of key actions need to be taken:

- Clarity about terminology and definition should be achieved so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.
- The debate about appropriate service design, workforce skills, etc. needs to be opened up. There needs to be better understanding of the similarities and differences of children and adults with PMLD compared with the rest of the population of people with learning disabilities.
- The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force.
- A PMLD sub-group should be formed and represented on the Task Force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- Partnership Boards should represent people with PMLD through advocates and family carers as a matter of course.
- People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.

Foreword about terminology

There is no universally recognised way of referring to the people who are identified by this network as having Profound and Multiple Learning Disability (PMLD). The White Paper uses a range of terminology. It refers to the following groups:

- 'children with severe disabilities and complex needs'
- 'people with additional or complex needs'
- 'people with severe learning disabilities and complex needs'
- 'children with complex medical needs'

- ‘profound learning disabilities’
- ‘young people with complex and multiple disabilities’
- ‘the most severely disabled’
- ‘those with more severe disabilities’
- ‘severe and profound disabilities (including those with sensory problems)’

When reviewing the content of the White Paper, we have taken these to indicate interest or intentions towards children and adults with PMLD.

However, this confusion in the use of terminology represents a difficulty that must be overcome in the future: if we do not know who we are talking about, how can we possibly understand what the issues are?

‘People with complex dependency needs are little known to the general public. Nor do authorities responsible for social policy and programmes and even the disability programmes in many countries properly know them. They are the excluded among the excluded’ (European Disability Forum 2000).

It is proposed here that this potential for exclusion can only be addressed by establishing a clear definition of profound and multiple learning disabilities. This will enable dialogue to take place about how support can best be designed and delivered.

Definitions

There are various published definitions of PMLD.

The World Health Organisation provides the following definition:

‘The IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only very rudimentary forms of non-verbal communication. They possess little or no ability to care for their own basic needs, and require constant help and supervision’ (WHO 1992)

One of the most useful definitions has been provided by Lacey (1988), who suggests that the term PMLD implies that the individual can be described as having both of the following:

1. Profound intellectual impairment
2. Additional disabilities, which may include sensory disabilities (e.g. visual impairment or hearing loss), physical disabilities and/or autism or mental illness. Challenging or self-injurious behaviour may also be present.

Based on WHO (1992) and DSMIV, the Multiple Disability Resource Team in the Oxfordshire Learning Disability NHS Trust developed a service definition in order to sort out the ongoing confusions within the service:

‘Children and adults with profound learning disability have extremely delayed intellectual and social functioning with little or no apparent understanding of verbal language and little or no apparent symbolic interaction with objects. They possess little or no ability to care for themselves. There is nearly always an associated medical factor such as neurological problems, physical dysfunction or pervasive developmental delay. In highly structured environments, with constant support and supervision and an individualised relationship with a carer, people with profound disabilities have the chance to engage with their world and to achieve optimum potential (which might mean even progress out of this classification as development proceeds). However, without structure and appropriate one-one support, such progress is unlikely.’ (Samuel & Pritchard 2001).

The main aim of providing a clear definition is to enable the development of a realistic approach to support, and a dialogue within a service about what constitutes good practice in providing person-centred support to individuals.

Recommendation

- Clarity about terminology and definition should be achieved so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.

The discussion below is based on the chapters in *‘Valuing People’*:

Chapter 1: Problems and challenges

How many people have profound and multiple learning disabilities?

The lack of agreement about the definition of profound and multiple learning disability means that it is hard to find accurate or recent statistics. Friars (1984) reviewed a number of studies which suggest that 1/1000 of the school population will have a 'profound disability'.

There is general agreement that this is the largest growing part of the population of people with learning disabilities. One survey revealed an increase in the number of children with PMLD entering special schools (Male 1996). A number of influences are reported as being responsible for the growth of this part of the population:

- More premature babies surviving
- Medical science prolonging lives that would have been lost in infancy
- People with PMLD are living longer.

(Carpenter 2000)

Recommendation

- The DOH should commission research into prevalence.
- Local authorities should be required to audit, record and monitor the number of children and adults with PMLD.
- The DOH National Survey should include children and adults with PMLD.

Inconsistency in service provision

Children and adults with PMLD are disadvantaged across the whole spectrum of services. They are more likely to be amongst the last of the long stay hospital population or living in larger congregate settings. It is generally acknowledged that only a very small part of this population has had access to some of the more innovative types of provision, such as support in living in a home of their own.

'People with high support needs often spend time in services, which have remained largely unchanged for 20 years. The health and social care systems, which replaced long-stay hospitals, were designed to offer a safe

environment, which could meet people's 'special needs'. As a result, many people with high support needs have continued to experience considerable social isolation and low expectations about having a place in the community' (McIntosh 2000).

Recommendations

- The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force. A PMLD sub-group should be formed and represented on the Task Force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- Partnership Boards should represent people with PMLD through advocates and family carers as a matter of course.
- People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.

Chapter 2: The new vision

Choice

In order to support the view that all people with a learning disability, including those with severe or profound disabilities, are able to make choices, the White Paper suggests that we need to develop 'the right help and support'.

There seems to be an assumption that everyone can make concrete choices if given the right communication aid (see page 1). However, the communication needs of children and adults with PMLD are complex. Many children and adults with PMLD have no formal means of communication, such as speech, signs or symbols. They may use a range of non-verbal means such as facial expression and body language, to communicate and be highly reliant on others to interpret these and enable them to be involved in choices and decisions. Because of this, they are often excluded.

The involvement of parents and the skills of carers are essential in supporting children and adults with PMLD to make choices. There is a need to develop the expertise to involve people with PMLD in the important choices, such as where and with whom they live and how they spend their time. This was focused on by the five community based projects which participated in the Choice Initiative. They demonstrated that with sufficient support and the establishment of good communication partnerships, important choices can be made (MHF 2000).

Example

When Raymond's parents took him to visit a group home, he was shown a big room that would be available to him. He smiled broadly and when it was time to leave he sat on the floor. This was his way of saying he felt comfortable. The family decided to make arrangements for him to move there and when they took him over with his possessions, he went straight to the room that is now his. He had made his choice.

(Alaszewski et al 1999)

Values Into Action suggest that all people are capable of 'supported decision making' if they have the opportunity to do so, if value is placed on the way they communicate their choices and if they are supported by a network of people who are committed to them (VIA 2001).

This is a challenging area needing much further work. However, only if there are sufficient resources and staff to listen to people's choices can relationships be maintained and people lead lives of their choice.

Recommendation

- All agencies need to recognise that people with profound and multiple learning disabilities can make choices when given the right support.

Chapter 3: Disabled children and young people

Problems and challenges

There is much emphasis in the White paper on increasing the number of children in receipt of a range of family support services, care and education in inclusive settings and those who use inclusive play, leisure and cultural services. The problems that children with PMLD face in accessing the range of services they need to meet their needs are about quality as well as quantity.

Children with PMLD and their parents face a number of potential barriers to using the services that are available to them. These include current difficulties resulting from Health and Safety lifting and handling regulations and the lack of appropriately trained staff to support ongoing health needs, such as the administration of certain kinds of medication e.g. rectal diazepam (Mencap 2000). Where services have failed to understand the issues, they have failed to design services to meet the needs. The result is that sometimes, when these services are offered, families cannot actually use them.

Example

Alison is 11. The social worker has offered to find her a place at an integrated summer playscheme for the school holidays. Her mother will have to pay for the place. There is no transport provided and her mother is anxious about how the large number of volunteers helping to run the scheme will be equipped to meet her feeding and continuing health care needs. She decides to keep her at home.

Complex health needs

Clarification is needed about the way in which the capital element of the Learning Disability Fund can be spent on this area.

As this is capital funding, it will be targeted at buildings and equipment. It may be that the intention here is to resolve the problems facing children using communication aids, special equipment and those who are technology-dependent due to complex health needs.

Whilst welcome in those terms, this statement is very misleading. It is a very narrow response to the much wider issues of care co-ordination. Children

with PMLD and their families receive services from a wide range of agencies, reflecting the diversity of their needs. They are often confused and frustrated in their attempts to make sense of this system. There is an urgent need for co-ordination by providing a single point of access to services via a single key-worker.

Example

Fiona is 3 years old with PMLD. She has a wide range of needs and is visited at home by a number of professionals from health, education and social services. Her mother calculated that there had been 18 different people she had had contact with over a three-month period. However, she was very confused about who they all were and where they came from. In addition, she still hadn't managed to get the support she needed to find Fiona a nursery place and had not received the special seating she had been assessed for.

There has been considerable work in the area of service co-ordination, such as that of the Social Policy Research Unit which has recently produced a resource pack aimed at developing a single point of access to services via one key-worker. This is work that needs taking forward so that the particular needs of children with PMLD can be addressed specifically (SPRU 2001).

Recommendation

- Parents of children and young people with PMLD should have one key worker who supports them and co-ordinates service provision.

Chapter 4: More choice and control for people with learning disabilities

Advocacy

People with PMLD are under-represented within the advocacy movement.

Citizen Advocacy can be a very effective form of advocacy for people with PMLD. However, many schemes experience difficulty in recruiting and retaining volunteers and advocates for these individuals. It may take time to get to know the individual and to build the kind of relationship that enables the citizen advocate to represent someone with PMLD meaningfully. The success of this approach seems to depend on several factors, such as good support for the advocate, training to enhance communication and feedback and contact with others taking on such roles.

These must be explored in greater depth.

People with a learning disability in established self-advocacy groups are beginning to express concern about those people who cannot speak for themselves, such as people with PMLD. The use of such peer advocacy is an area that needs further exploration and evaluation.

Circles of support

Through the CREDO Project (part of the Circles Network), it has been very apparent that circles of support are of great value when supporting individuals with PMLD.

With a circle of support there is usually a relationship already established. Many circles include family members, friends and, sometimes, staff who know the individual well. Although some inevitably move out of people's circles and new people are introduced, responsibilities are shared so no one person holds all relevant information and if one person leaves, the support, empowerment and advocacy for the individual are able to continue and grow.

By using those people already known to the person as a resource, services and agencies are able to get a clearer, truer picture of who the individual is and what their goals and support needs are. They should then, in theory, be in a position to respond quickly and more effectively.

It is becoming more and more apparent that using circles of support is one of the best ways of assisting a person with PMLD to get the right support and have control over their lives. There are gradually more examples coming through of circles of support being used to manage direct payments by setting up an Independent Service User Trust. (VIA 2001). However, those that currently exist appear to have come about because of the tenacity of the individual's family. There are many more people with PMLD who would benefit from this opportunity but may not have this kind of support available to them.

Person centred planning

Person centred planning has the potential to make a substantial difference to people with PMLD, especially if linked to circles of support. Examples of using this approach with people with PMLD suggest that this could inspire the creativity and imagination needed to provide the high quality, individualised services that are desperately needed in this area.

There has been some progress in facilitating this process for people with PMLD by involving those people who know the individual best, including family members. The benefit of involving a wider group of people is that there will be a shared commitment to follow through actions and ensure that a plan is put together appropriately and listened to.

The process of person centred planning has also been shown to be an incredibly positive experience for families who have often been discouraged from 'dreaming' for their child, right from the point of diagnosis.

Involvement in policy development and decision making

We have come a long way in our understanding of non-verbal communication and in involving people with complex communication needs in decision making and choice but much still needs to be done. We are still some distance from being able to include people with PMLD meaningfully in policy development. However, it is too often the case that the perceived difficulties in involving children and adults with PMLD result in them remaining excluded.

There is exciting work being developed by organisations such as 'Acting Up' in the area of multi-media profiling (Ladle 2000), Circles Network and some citizen advocacy groups. Initiatives such as these need greater investment and support so that people with PMLD can achieve greater choice and control over their lives.

There is a need to consider the issue of greater user representation and involvement in policy making.

Direct payments

The example included in '*Valuing People*' (see below) challenges the assumption, made by many, that direct payments are not applicable to people with PMLD as they cannot manage them. It is the experience of members of the PMLD Network that families are having to fight long and hard to secure direct payments for their sons and daughters with PMLD. Where they have succeeded in doing so, the outcomes appear to have had a significant impact on the quality of life of both individuals with PMLD and their parents and carers.

Example taken from 4.14 in Valuing People

'Susan, who is nearly in her 20's, is severely disabled. She makes her views known through her actions, verbal responses, facial expressions and moods. Susan's circle of support realised she was unhappy with her existing services and put together a package of money to enable her to live independently. Direct payments are part of the package. The circle formed itself into a user-controlled fund, which manages the direct payment. Susan's expressions and views guide how money is spent, so she is in control of the use of the money. Direct payments mean Susan can live in her own house with her own rota of support workers. She is relaxed, confident and content with a full social life and is very much part of the community.'

If people with PMLD and their families are to take advantage of this initiative, there is a need for clear information and access to the support needed to achieve it, such as the work being done by Values Into Action.

Communication and equipment

As already stated (p.6 Choice), the communication needs of children and adults with PMLD are complex. It also needs to be understood that whilst some people with PMLD will clearly benefit from the use of technology, there are many for whom it will prove too challenging. It is an important strand of the work needed in the area of communication for people with PMLD, but not a total solution.

It is important to encourage the development of any technology, which may support the communication of children and adults with PMLD. But the equipment is only ever as good as the team of people supporting the individual to use it.

There are many people with disabilities who have the potential to learn how to use electronic communication equipment, but few are given the opportunity. Acquiring the skills to use a high-tech system can take months or years of extremely hard work. It requires the individual, his/her supporters in all environments and specialist healthcare professionals to work together and sustain motivation and a consistent approach.

Technology is never a replacement for basic yet fundamental changes that supporters can make to everyday communication. Communication skills are central to achieving real participation and it is essential that this area is given high priority for any individual with PMLD.

It should also be noted that children and adults with PMLD often have complex physical disabilities and that these can mask intellectual abilities. This is one reason that those working with such children and adults need to proceed on the assumption that any individual may be able to make use of communication technology.

Example

Danny is 29 years old and has cerebral palsy, which affects his mobility and ability to control his upper limb and head movement. He uses a wheelchair and requires support in all aspects of his life.

Until three years ago Danny's only method of expressing himself had been through facial expression, vocalising and a somewhat haphazard yes/no response using one blink for 'yes' and two for 'no'. Everyone involved in Danny's life had always felt that he should have been able to use a communication aid. However, the difficulties he experienced in controlling his limbs and his many involuntary movements had meant that no one had ever been able to establish a method of assessing his level of understanding and therefore, never attempted to introduce such a system.

Three years on, Danny now uses a fairly sophisticated electronic speech output aid which allows him to express needs, wishes, opinions, emotions and social language. This would not have been possible without the following assurances:

- A consistent and cohesive staff team at home and day service
- A regular team of health professionals with expertise in working with people with PMLD
- A positive attitude from all involved and the ability to problem solve
- A detailed plan for implementing the aid
- Signed agreements from all involved of their commitment to using the aid and to changing the way in which they communicated with Danny so that he had as many opportunities as possible to use his aid (i.e. not resorting to the yes/no questions)
- Regular meetings to review the implementation plan, to share information and to iron out any problems
- A method of daily communication between all on progress

This type of communication aid would only meet the cognitive needs of some children and adults with PMLD. However, it is felt that no communication aid (whether that be objects of reference, communication passports etc) would ever prove to be truly functional without the consistent and detailed approach outlined above.

Recommendation

- Further funding should be given to citizen advocacy schemes to ensure that people with PMLD have access to an advocate.
- Agencies should be required to have communication plans, which focus on meeting individual needs.
- People with PMLD should be given priority for person centred planning.
- Those responsible for policy development should ensure that they take account of the needs of people with PMLD.

Chapter 5: Supporting carers

Problems and challenges

The needs of parents and carers have been recognised to a certain extent in Valuing People. The role of parents of children and adults with PMLD is of particular significance because of the intensity and specialised nature of those caring responsibilities.

Research has shown that the number and range of daily care responsibilities undertaken by families is wide and daunting, such as the fact that, on average, they spend eight and a half hours per day in activities such as physical management (lifting, handling and positioning), basic care activities (dressing, bathing, toileting and assistance at mealtimes) and, in some cases, management of medical conditions like epilepsy (Hogg & Lambe 1988). This has remained one of the few substantial pieces of research that has focused on the needs of the parents of children and adults with PMLD. However, it is apparent that there has been little improvement in the support given to these families in the last 13 years.

A recent Mencap survey found that the combined time spent on basic care needs, educational and therapeutic needs and entertaining or simply being with individuals who could not be left unattended, was an average of 18 hours a day. In addition parents were woken an average of three times per night. Many families felt that they are very poorly supported by services and felt that their role and in-depth knowledge is not valued by professionals ('No Ordinary Life', Mencap 2001).

In addition, many families reported that they could not make use of the services offered, as service providers have failed to overcome a range of issues that have become barriers to using services, such as invasive care needs and lifting and handling regulations. It is simply not good enough to offer families services such as a home sitting service that has a 'no lifting policy' or that cannot administer rectal diazepam.

There appears to be a limited understanding of the kind of holistic family support needed. Further, in developing initiatives, which clearly benefit their more able peer group, services have failed to take account of the particular impact on people with PMLD and their families. By not doing so, they may be further disadvantaged. An example of this may be seen within the programme aimed at modernising day services. Some new models exclude a resource centre or base from which to operate and do not offer a full week's

timetable. It is not reasonable to expect parents either to use their own home as a base or to fill in vacant parts of the week by providing the care themselves. The caring task they already have is huge. 25-year-olds do not usually spend their days relying on the support of their parents, so why should people with PMLD?

Example

Jennifer is 42 with profound and multiple learning disabilities. She lives at home with her parents who are now in their 70s. Jennifer uses a wheelchair and has severe epilepsy and this means that there are lifting and handling issues, as well as the need to administer rectal diazepam should she go in to status epilepticus. A respite carer has been provided by social services but, following a risk assessment, it has been stated that this worker cannot do any lifting as Jennifer needs two people to lift her and they do not have enough resources to send two workers. She is not trained to administer rectal diazepam. She can only sit with Jennifer and so her parents cannot leave the house.

It is hard to imagine how these families sustain these levels of care day after day, night after night, without practical hands-on help from services. There is a need to prioritise the practical and emotional needs of such families and to identify more effective means of support.

Recommendations

- The needs of family carers should be identified as a priority.
- Family carers should have access to home based and/or residential short break services to support them in their caring role.

Chapter 6: Improving health for people with learning disabilities

Problems and challenges

Health is a particularly significant area for children and adults with PMLD, many of whom have complex health needs. There appear to be great difficulties in meeting a range of specialist and general health needs. Many parents describe the difficulties they experience in enabling their sons and daughters to access basic medical care:

‘My daughters are considered totally worthless. They are not treated like normal people. They cannot even get access to hospital treatment, not even basic nursing care...’ (Parent)

Various studies of the health needs of children and adults with PMLD demonstrate a high prevalence of severely underweight individuals, a higher prevalence of epilepsy, a high risk of pressure sores, a disproportionate amount of respiratory infection and a generally higher level of health care needed (Hutchinson 1988). In contrast, health care has been reported as poor. In one study of a group of people with PMLD who were given a health check, 92% were found to have a previously undetected but treatable condition (Meehan 1995).

There are also some services that people with PMLD have very little access to at all - in particular, mental health services. These are another example of how we accept the demeanour and behaviour of someone with PMLD as part of their overall disability and fail to recognise the signals they are giving us that something is not right. The mental health needs of young people with profound and multiple learning disabilities will be included in ‘The enquiry into meeting the mental health needs of young people’ led by the Foundation for People with Learning Disabilities (October 2001).

Intensive health care support

Children and adults with PMLD will require specialist support at various times. One example of a key health issue is swallowing disorders. These can cause malnutrition, dehydration and pneumonia as well as triggering associated health risks, such as susceptibility to infections, difficulties with wound healing and impairment to mental and physical function. People with swallowing disorders require access to specialist health professionals

and assessments, including a videofluoroscopy and interventions ranging from thickeners for drinks to gastrostomies.

Whilst we must be careful not to over-medicalise their needs, we must ensure access to high quality specialist health services when they are needed.

Health checks and addressing inequalities in health care

It would be very beneficial for people with PMLD to have access to regular health screening. Establishing the 'norm' for someone with PMLD, which can be complex in itself, will provide an important baseline in understanding the often subtle changes indicating the need for further investigation. Self-injuring behaviour, loss of appetite or a decrease in interaction for example, may all be vital pieces of information indicating a change in physical or emotional well being. The role of the proposed health facilitators could be extremely useful here.

Recommendations

- Children and adults with PMLD should have annual health checks.
- Children and adults with PMLD should be given priority in establishing the use of health facilitators.

Chapter 7: Housing, fulfilling lives and employment

Housing

People with PMLD can benefit from the full range of housing options when re-provisioning plans are developed. There is increasing expertise in this area, such as the housing advice given by the organisation 'Housing Options'. The following example illustrates their work:

Example

Rebecca is a young woman in her late 20's. She has profound and multiple learning disabilities (PMLD) and severe epilepsy. She was living in a large registered care home. It was an out of county placement, as her local authority considered her to be 'too disabled for them to provide for her care needs'. She was unhappy, sometimes wheeling herself into the corner of the room and scratching herself. Her parents were unhappy and wanted to do something better. The home she was in was due to close so something had to happen. Her father had just retired and dedicated himself to finding something different and it took several years before she arrived at her current situation.

Rebecca had a 'care assessment'. This concluded that Rebecca was unhappy and that she needed high levels of care and support. Her need to live with fewer people was raised as an option. Her parents decided that they would like Rebecca to have her own home and wrote to a housing association. The HA put together a bid for a bungalow but it was rejected as 'poor value for money'. A second bid was made for 'shared ownership'. In this option the HA is usually the partner. In grant terms, this is cheaper and at last the bid became 'good value'. The bungalow was built specifically for her needs. All facilities are fully accessible. It is the first time that Rebecca has been allowed in the kitchen! There are doors to the patio and a garden, a big bedroom with an en-suite bathroom and a 'drive in' shower. There are 3 bedrooms. She needs 24-hour care so one bedroom is for care staff and the third is a laundry. The house is next door to her parents. They can see her every day and, in effect, supervise the care. Recently the parents have set up a small company and employ the 6-7 staff needed themselves. The cost to the LA is the same as it was when Rebecca was at the out of county residential service, about £1,200 per week. (King 1988)

Those responsible for housing needs will often quote the cost, as well as the fragility, vulnerability and high support needs of people with PMLD as reasons not to consider more options.

This case study demonstrates the possibilities for a very profoundly disabled person to live in their own home without a huge increase in cost but, enjoying a huge increase in their quality of life. This is demonstrated by things like a significant improvement in communication skills.

However, these examples are very much in the minority and have often only come about because of determined parents. One account is given by Jean Wilson and Pat Fitton who wanted their daughters to have a home of their own. It tells of the difficulties they had to overcome to achieve this finally (Fitton, O'Brien and Wilson 1995). These accounts are inspiring but for many parents, who may be desperately tired after years of caring, they appear beyond reach.

Modernising day services

The White Paper recognises that there is a need to think very carefully about day services for people with PMLD.

There is much that people with PMLD can take part in within a community setting. There is also a strong need to increase their participation in community life. Some activities do not have to be provided within a special setting. A market, shopping centre or café can provide a stimulating multi-sensory experience for some people. However, many people with PMLD need specialised activities, such as daily physiotherapy or a hydrotherapy pool, rather than the local leisure centre's pool.

The closure of larger day centres and the move to more community based smaller centres has frequently had a substantial and negative impact on people with PMLD. There has been less contact with more able people with a learning disability (and a correspondingly less stimulating environment), an increase in segregation and a decline in the range and quality of activities.

This is largely because many service providers have not taken on board some of the additional needs of people with PMLD such as lifting and handling, health needs, and special forms of transport, and have allocated insufficient resources to enable them to take part in community-based opportunities. For example, there are currently very few facilities in the community that have adult sized changing areas. This means that some form of building based service may be needed.

There is no reason why people with PMLD should not enjoy real activities in the community and build their own circle of friends. But for this to happen, services must address the resource issues, staff skills and the practical challenges of meeting diverse needs in an imaginative way. If they fail to do so there is a high risk that people with PMLD will become increasingly excluded from a crucial service.

Recommendations

- The modernisation of day services programme should be planned, monitored and evaluated with the needs of people with PMLD in mind.

Chapter 8: Quality services

People with additional and complex needs

This section of the White Paper conveys some understanding of the range of needs that have to be addressed and the array of services that need to be able to respond. These services must be able to provide the very specialist skills required for a significant improvement in the quality of support.

There is a shortage of therapists in general, particularly those with the expertise needed for children and adults with PMLD. Historically, many services have not prioritised people with PMLD against the competing demands of their more able peer group. There is a culture of under-investing in people with PMLD and in those responsible for their care.

All staff need to have access to training that addresses the specific needs of people with PMLD. Failing to support staff in gaining the skills they need results in people with PMLD typically and routinely receiving less attention and support from staff than those with more moderate needs.

Staff turnover is high in services for people with PMLD, often reflecting the feeling of helplessness and perceived lack of feedback. This is a direct result of the lack of appropriate staff training. Staff working with children and adults with PMLD need to be trained in specialised skills such as effective communication strategies, multi-sensory approaches and Intensive Interaction (Nind and Hewett 2001).

Recommendations

- Health professionals should receive additional training to ensure that people with PMLD have equal access to the services they provide.
- Induction training for care staff should include information on the needs of children and adults with PMLD.
- Staff working directly with children and adults with PMLD should have access to high quality training, in particular, communication skills training.

Chapter 9: Making change happen

It is significant that there are no specific objectives for people with PMLD within this final section. It is also clear that if children and adults with PMLD are to benefit from the initiatives set out in the White Paper, there are implications affecting resources.

In putting forward a range of views, examples and ideas, the PMLD Network has attempted to illustrate the overall point that children and adults with PMLD are amongst the most excluded people in our society. Unless we focus our attention on their particular needs in a comprehensive and holistic way, they are in danger of remaining so.

‘Perhaps the single biggest barrier lies in our low expectations and failures of imagination.’ (Steve Beyer 2000)

Overall, the task is to develop our understanding of the needs of children and adults with PMLD and to design services that are truly inclusive of their particular needs. Only then will we be able to respond to the challenge of ‘enabling extraordinary people to live ordinary lives.’ (McConkey 1998)

A vision for the future: Katy and Gemma’s story

Gemma (23) and her friend Katy (22) have profound and multiple learning disabilities. Neither Gemma nor Katy has any spoken language and Gemma uses a wheelchair. Katy has serious eating problems and until recently was very underweight. Gemma’s mother, Jan and Katy’s mother, Wendy, who had been friends since the girls started school together, began to look to the future in terms of residential care.

As they began to consider the various residential options available to them, they became very concerned and depressed because there was very little on offer. The options were far away from home and none seemed able to offer anything like their current home lives.

In desperation, Wendy and Jan decided to get together and write a vision for their daughters’ happiness. They didn’t know it at the time, but what they produced was very much like a person centred plan. This vision formed the basis of a comprehensive booklet detailing the exact level of support they needed and how it should be provided. It also set out the two main objectives of finding a suitable bungalow and arranging for its purchase and secondly obtaining the funding for the support. They presented the document to the local social services department in Oxfordshire. It was well

received, but the story of how their vision was eventually achieved is a long one with Wendy and Jan having to overcome many hurdles before realising the dream, after more than two years of intense negotiation.

However, Gemma and Katy are now tenants of a large bungalow, re-designed inside from two small adjoining properties. They have a circle of support, the members of which are trustees of a Supported Living Trust. This ensures that Gemma and Katy's wishes and choices remain central to any decisions made and that their direct payments are used to best advantage on their behalf.

Gemma and Katy have been living in their home for over two years now and they are both happy and flourishing. They have a team of seven staff, including a team leader and together they form a very cohesive group. Gemma's mum still does an occasional shift at the home when needed and both women stay with their families regularly. Gemma and Katy now have Essential Life-style Plans, which are updated regularly ensuring they continue to lead the lives they choose.

'As a parent, it is wonderful to be able to visit my daughter whenever I want and feel completely at ease and welcome. I am absolutely confident that our daughters are having the best life that they could possibly lead surrounded by people who care about them as individuals - and with the sort of partnership we all enjoy, I feel sure it can only get better.' (Jan Roast, Gemma's mother)

Summary of recommendations

- 1) Clarity about terminology and definitions so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.
- 2) The DOH should commission research into prevalence.
- 3) Local authorities should be required to audit, record and monitor the number of children and adults with PMLD.
- 4) The DOH National Survey should include children and adults with PMLD.
- 5) The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force. A PMLD sub-group should be formed and represented on the task force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- 6) Partnership Boards should represent people with PMLD, as a matter of course.
- 7) People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.
- 8) All agencies need to recognise that people with profound and multiple learning disabilities can make choices when given the right support.
- 9) Parents of children and young people with profound and multiple learning disabilities should have one key worker who supports them and co-ordinates service provision.
- 10) Further funding should be given to citizen advocacy schemes to ensure that people with PMLD have access to an advocate.
- 11) Agencies should be required to have communication plans, which focus on meeting individual needs.
- 12) People with PMLD should be given priority for person centred planning.
- 13) Those responsible for policy development should ensure that they take account of the needs of people with PMLD.

- 14) The needs of family carers of children and adults with PMLD should be identified as a priority.
- 15) Family carers should have access to home-based and/or residential short break services to support them in their caring role.
- 16) Children and adults with PMLD should have annual health checks
- 17) Children and adults with PMLD should be given priority in establishing the use of health facilitators.
- 18) The modernisation of day services programme should be planned, monitored and evaluated with the needs of people with PMLD in mind.
- 19) Health professionals should receive additional training to ensure that people with PMLD have equal access to the services they provide.
- 20) Induction training for care staff should include information on the needs of children and adults with PMLD.
- 21) Staff working directly with children and adults with PMLD should have access to high quality training, in particular, communication skills training.

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PMLD Network Membership List

Steve Carnaby	Lecturer in Learning Disability, Tizard Clinical Psychologist, Parkside NHS Trust
Beverley Dawkins	National Officer for Profound and Multiple Learning Disabilities, Mencap
Nadine Jay	Project Co-ordinator Circles Network, Credo Project
Wendy Lewington	National Advocacy Co-ordinator, Scope
Gudrun Limbrick	Trustee The Hansel Trust
Hazel Morgan	Head of the Foundation for People with Learning Disabilities
Jan Roast	Parent
Sarah Robertson	Resource for Opportunity and Change (ROC)
Judith Samuel	British Psychological Society Division of Clinical Psychology Special Interest Group (Learning Disability) Consultant Clinical Psychologist and Co-ordinator of the Multiple Disability Resource Team Oxfordshire's Learning Disability Trust
Laura Waite	Royal National Institute for the Blind

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Introduction

In November 2000 Mencap and the Foundation for People with Learning Disabilities brought together a small group from other organisations (membership list attached) with an interest and expertise in working with children and adults with profound and multiple learning disabilities and their parents and carers. The group, now known as the PMLD Network, agreed that its first task should be to provide a response to the forthcoming White Paper and work to influence its implementation.

Children and adults with PMLD are probably some of the most marginalised people within our society, have some of the highest support needs and are more reliant on services. There is a need for action at every level of service provision. For these reasons, it was hoped that the White Paper would make specific recommendations and set out targets for people with PMLD.

The PMLD Network welcomes the principles set out in the White Paper and believes that '*Valuing People*' has raised some important issues that are relevant to children and adults with PMLD. However, we feel that the range of initiatives set out in the document will only benefit these individuals in the context of greater consideration of the issues that confront both children and adults with PMLD and their parents and carers.

It is our view that '*Valuing People*' does not fully address the issues for children and adults with PMLD. This is apparent in the way that it does not:

- use consistent terminology
- identify that children and adults with PMLD are amongst the most excluded people in our society
- identify children and adults with PMLD as a priority group
- make any specific objective or sub-objective for people with PMLD
- identify family carers of children and adults with PMLD as a priority group.

In many ways it could be said that '*Valuing People*' accurately reflects the problems facing children and adults with PMLD - we don't know how to describe them and therefore we don't know how to accumulate the information we require to gain an accurate picture of their needs. We are aware that we are not doing enough and that we will need to do more. Sometimes we do not think about the issues sufficiently and make changes in services that actually further disadvantage children and adults with PMLD (Samuel & Pritchard 2001).

We therefore feel that there is a great deal of work to be done to support and influence the implementation of the White Paper and will be setting out what we see as the critical issues for children and adults with PMLD in more detail in this paper.

Principles

We believe that if we are to take effective action on behalf of children and adults with PMLD there needs to be agreement about the principles we have set out below:

- **Vision:** we need to understand that whilst the overall vision is the same as for their more able peer group, the detail for children and adults with PMLD is often different. Children and adults with PMLD have specific needs that call for specific initiatives. All too often, their needs are lost within the wider agenda. This is why, at this stage, it is important to identify them as a group and focus on their additional needs with greater clarity.
- **Values:** to want to take action we need to believe that all people have value. Many parents and carers of children and adults with PMLD say that their sons and daughters are not valued and that their contribution to society is not properly acknowledged. Judgements are made about the meaning and quality of their lives. We know that children and adults with PMLD may experience the world in a different way, but also that their lives may be enriched by the things that we all share: for example, the company of friends and family, music or the taste of food. In turn, they enrich the lives of others. We need to promote the positive contribution of children and adults with PMLD.
- **Visibility:** Many people in our society simply do not know that children and adults with PMLD exist. Others have failed to understand their needs in a coherent way and have not planned for the kind of services that meet their needs. We need to make them visible.
- **Rights:** It seems necessary to state that children and adults with PMLD have the same rights as anyone else. It is necessary to reiterate this because by failing to translate those rights into actions that directly improve the quality of their lives, we actually deny those rights. We need to campaign for the rights of children and adults with PMLD.
- **Representation:** The advocacy movement has done much to enable people with a learning disability in general, to take their rightful place in society, but people with PMLD have had little part of this. We need to address the issue of meaningful representation.

Taking action

'Valuing People' has touched upon some important issues that could be relevant to people with PMLD, including a range of initiatives which could substantially benefit people with PMLD if the work is done to influence and support their implementation. However, if any real impact is to be made on the lives of children and adults with PMLD, a number of key actions need to be taken:

- Clarity about terminology and definition should be achieved so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.
- The debate about appropriate service design, workforce skills, etc. needs to be opened up. There needs to be better understanding of the similarities and differences of children and adults with PMLD compared with the rest of the population of people with learning disabilities.
- The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force.
- A PMLD sub-group should be formed and represented on the Task Force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- Partnership Boards should represent people with PMLD through advocates and family carers as a matter of course.
- People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.

Foreword about terminology

There is no universally recognised way of referring to the people who are identified by this network as having Profound and Multiple Learning Disability (PMLD). The White Paper uses a range of terminology. It refers to the following groups:

- 'children with severe disabilities and complex needs'
- 'people with additional or complex needs'
- 'people with severe learning disabilities and complex needs'
- 'children with complex medical needs'

- ‘profound learning disabilities’
- ‘young people with complex and multiple disabilities’
- ‘the most severely disabled’
- ‘those with more severe disabilities’
- ‘severe and profound disabilities (including those with sensory problems)’

When reviewing the content of the White Paper, we have taken these to indicate interest or intentions towards children and adults with PMLD.

However, this confusion in the use of terminology represents a difficulty that must be overcome in the future: if we do not know who we are talking about, how can we possibly understand what the issues are?

‘People with complex dependency needs are little known to the general public. Nor do authorities responsible for social policy and programmes and even the disability programmes in many countries properly know them. They are the excluded among the excluded’ (European Disability Forum 2000).

It is proposed here that this potential for exclusion can only be addressed by establishing a clear definition of profound and multiple learning disabilities. This will enable dialogue to take place about how support can best be designed and delivered.

Definitions

There are various published definitions of PMLD.

The World Health Organisation provides the following definition:

‘The IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such individuals are immobile or severely restricted in mobility, incontinent, and capable at most of only very rudimentary forms of non-verbal communication. They possess little or no ability to care for their own basic needs, and require constant help and supervision’ (WHO 1992)

One of the most useful definitions has been provided by Lacey (1988), who suggests that the term PMLD implies that the individual can be described as having both of the following:

1. Profound intellectual impairment
2. Additional disabilities, which may include sensory disabilities (e.g. visual impairment or hearing loss), physical disabilities and/or autism or mental illness. Challenging or self-injurious behaviour may also be present.

Based on WHO (1992) and DSMIV, the Multiple Disability Resource Team in the Oxfordshire Learning Disability NHS Trust developed a service definition in order to sort out the ongoing confusions within the service:

‘Children and adults with profound learning disability have extremely delayed intellectual and social functioning with little or no apparent understanding of verbal language and little or no apparent symbolic interaction with objects. They possess little or no ability to care for themselves. There is nearly always an associated medical factor such as neurological problems, physical dysfunction or pervasive developmental delay. In highly structured environments, with constant support and supervision and an individualised relationship with a carer, people with profound disabilities have the chance to engage with their world and to achieve optimum potential (which might mean even progress out of this classification as development proceeds). However, without structure and appropriate one-one support, such progress is unlikely.’ (Samuel & Pritchard 2001).

The main aim of providing a clear definition is to enable the development of a realistic approach to support, and a dialogue within a service about what constitutes good practice in providing person-centred support to individuals.

Recommendation

- Clarity about terminology and definition should be achieved so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.

The discussion below is based on the chapters in *‘Valuing People’*:

Chapter 1: Problems and challenges

How many people have profound and multiple learning disabilities?

The lack of agreement about the definition of profound and multiple learning disability means that it is hard to find accurate or recent statistics. Friars (1984) reviewed a number of studies which suggest that 1/1000 of the school population will have a 'profound disability'.

There is general agreement that this is the largest growing part of the population of people with learning disabilities. One survey revealed an increase in the number of children with PMLD entering special schools (Male 1996). A number of influences are reported as being responsible for the growth of this part of the population:

- More premature babies surviving
- Medical science prolonging lives that would have been lost in infancy
- People with PMLD are living longer.

(Carpenter 2000)

Recommendation

- The DOH should commission research into prevalence.
- Local authorities should be required to audit, record and monitor the number of children and adults with PMLD.
- The DOH National Survey should include children and adults with PMLD.

Inconsistency in service provision

Children and adults with PMLD are disadvantaged across the whole spectrum of services. They are more likely to be amongst the last of the long stay hospital population or living in larger congregate settings. It is generally acknowledged that only a very small part of this population has had access to some of the more innovative types of provision, such as support in living in a home of their own.

'People with high support needs often spend time in services, which have remained largely unchanged for 20 years. The health and social care systems, which replaced long-stay hospitals, were designed to offer a safe

environment, which could meet people's 'special needs'. As a result, many people with high support needs have continued to experience considerable social isolation and low expectations about having a place in the community' (McIntosh 2000).

Recommendations

- The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force. A PMLD sub-group should be formed and represented on the Task Force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- Partnership Boards should represent people with PMLD through advocates and family carers as a matter of course.
- People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.

Chapter 2: The new vision

Choice

In order to support the view that all people with a learning disability, including those with severe or profound disabilities, are able to make choices, the White Paper suggests that we need to develop ‘the right help and support’.

There seems to be an assumption that everyone can make concrete choices if given the right communication aid (see page 1). However, the communication needs of children and adults with PMLD are complex. Many children and adults with PMLD have no formal means of communication, such as speech, signs or symbols. They may use a range of non-verbal means such as facial expression and body language, to communicate and be highly reliant on others to interpret these and enable them to be involved in choices and decisions. Because of this, they are often excluded.

The involvement of parents and the skills of carers are essential in supporting children and adults with PMLD to make choices. There is a need to develop the expertise to involve people with PMLD in the important choices, such as where and with whom they live and how they spend their time. This was focused on by the five community based projects which participated in the Choice Initiative. They demonstrated that with sufficient support and the establishment of good communication partnerships, important choices can be made (MHF 2000).

Example

When Raymond’s parents took him to visit a group home, he was shown a big room that would be available to him. He smiled broadly and when it was time to leave he sat on the floor. This was his way of saying he felt comfortable. The family decided to make arrangements for him to move there and when they took him over with his possessions, he went straight to the room that is now his. He had made his choice.

(Alaszewski et al 1999)

Values Into Action suggest that all people are capable of ‘supported decision making’ if they have the opportunity to do so, if value is placed on the way they communicate their choices and if they are supported by a network of people who are committed to them (VIA 2001).

This is a challenging area needing much further work. However, only if there are sufficient resources and staff to listen to people's choices can relationships be maintained and people lead lives of their choice.

Recommendation

- All agencies need to recognise that people with profound and multiple learning disabilities can make choices when given the right support.

Chapter 3: Disabled children and young people

Problems and challenges

There is much emphasis in the White paper on increasing the number of children in receipt of a range of family support services, care and education in inclusive settings and those who use inclusive play, leisure and cultural services. The problems that children with PMLD face in accessing the range of services they need to meet their needs are about quality as well as quantity.

Children with PMLD and their parents face a number of potential barriers to using the services that are available to them. These include current difficulties resulting from Health and Safety lifting and handling regulations and the lack of appropriately trained staff to support ongoing health needs, such as the administration of certain kinds of medication e.g. rectal diazepam (Mencap 2000). Where services have failed to understand the issues, they have failed to design services to meet the needs. The result is that sometimes, when these services are offered, families cannot actually use them.

Example

Alison is 11. The social worker has offered to find her a place at an integrated summer playscheme for the school holidays. Her mother will have to pay for the place. There is no transport provided and her mother is anxious about how the large number of volunteers helping to run the scheme will be equipped to meet her feeding and continuing health care needs. She decides to keep her at home.

Complex health needs

Clarification is needed about the way in which the capital element of the Learning Disability Fund can be spent on this area.

As this is capital funding, it will be targeted at buildings and equipment. It may be that the intention here is to resolve the problems facing children using communication aids, special equipment and those who are technology-dependent due to complex health needs.

Whilst welcome in those terms, this statement is very misleading. It is a very narrow response to the much wider issues of care co-ordination. Children

with PMLD and their families receive services from a wide range of agencies, reflecting the diversity of their needs. They are often confused and frustrated in their attempts to make sense of this system. There is an urgent need for co-ordination by providing a single point of access to services via a single key-worker.

Example

Fiona is 3 years old with PMLD. She has a wide range of needs and is visited at home by a number of professionals from health, education and social services. Her mother calculated that there had been 18 different people she had had contact with over a three-month period. However, she was very confused about who they all were and where they came from. In addition, she still hadn't managed to get the support she needed to find Fiona a nursery place and had not received the special seating she had been assessed for.

There has been considerable work in the area of service co-ordination, such as that of the Social Policy Research Unit which has recently produced a resource pack aimed at developing a single point of access to services via one key-worker. This is work that needs taking forward so that the particular needs of children with PMLD can be addressed specifically (SPRU 2001).

Recommendation

- Parents of children and young people with PMLD should have one key worker who supports them and co-ordinates service provision.

Chapter 4: More choice and control for people with learning disabilities

Advocacy

People with PMLD are under-represented within the advocacy movement.

Citizen Advocacy can be a very effective form of advocacy for people with PMLD. However, many schemes experience difficulty in recruiting and retaining volunteers and advocates for these individuals. It may take time to get to know the individual and to build the kind of relationship that enables the citizen advocate to represent someone with PMLD meaningfully. The success of this approach seems to depend on several factors, such as good support for the advocate, training to enhance communication and feedback and contact with others taking on such roles.

These must be explored in greater depth.

People with a learning disability in established self-advocacy groups are beginning to express concern about those people who cannot speak for themselves, such as people with PMLD. The use of such peer advocacy is an area that needs further exploration and evaluation.

Circles of support

Through the CREDO Project (part of the Circles Network), it has been very apparent that circles of support are of great value when supporting individuals with PMLD.

With a circle of support there is usually a relationship already established. Many circles include family members, friends and, sometimes, staff who know the individual well. Although some inevitably move out of people's circles and new people are introduced, responsibilities are shared so no one person holds all relevant information and if one person leaves, the support, empowerment and advocacy for the individual are able to continue and grow.

By using those people already known to the person as a resource, services and agencies are able to get a clearer, truer picture of who the individual is and what their goals and support needs are. They should then, in theory, be in a position to respond quickly and more effectively.

It is becoming more and more apparent that using circles of support is one of the best ways of assisting a person with PMLD to get the right support and have control over their lives. There are gradually more examples coming through of circles of support being used to manage direct payments by setting up an Independent Service User Trust. (VIA 2001). However, those that currently exist appear to have come about because of the tenacity of the individual's family. There are many more people with PMLD who would benefit from this opportunity but may not have this kind of support available to them.

Person centred planning

Person centred planning has the potential to make a substantial difference to people with PMLD, especially if linked to circles of support. Examples of using this approach with people with PMLD suggest that this could inspire the creativity and imagination needed to provide the high quality, individualised services that are desperately needed in this area.

There has been some progress in facilitating this process for people with PMLD by involving those people who know the individual best, including family members. The benefit of involving a wider group of people is that there will be a shared commitment to follow through actions and ensure that a plan is put together appropriately and listened to.

The process of person centred planning has also been shown to be an incredibly positive experience for families who have often been discouraged from 'dreaming' for their child, right from the point of diagnosis.

Involvement in policy development and decision making

We have come a long way in our understanding of non-verbal communication and in involving people with complex communication needs in decision making and choice but much still needs to be done. We are still some distance from being able to include people with PMLD meaningfully in policy development. However, it is too often the case that the perceived difficulties in involving children and adults with PMLD result in them remaining excluded.

There is exciting work being developed by organisations such as 'Acting Up' in the area of multi-media profiling (Ladle 2000), Circles Network and some citizen advocacy groups. Initiatives such as these need greater investment and support so that people with PMLD can achieve greater choice and control over their lives.

There is a need to consider the issue of greater user representation and involvement in policy making.

Direct payments

The example included in '*Valuing People*' (see below) challenges the assumption, made by many, that direct payments are not applicable to people with PMLD as they cannot manage them. It is the experience of members of the PMLD Network that families are having to fight long and hard to secure direct payments for their sons and daughters with PMLD. Where they have succeeded in doing so, the outcomes appear to have had a significant impact on the quality of life of both individuals with PMLD and their parents and carers.

Example taken from 4.14 in Valuing People

'Susan, who is nearly in her 20's, is severely disabled. She makes her views known through her actions, verbal responses, facial expressions and moods. Susan's circle of support realised she was unhappy with her existing services and put together a package of money to enable her to live independently. Direct payments are part of the package. The circle formed itself into a user-controlled fund, which manages the direct payment. Susan's expressions and views guide how money is spent, so she is in control of the use of the money. Direct payments mean Susan can live in her own house with her own rota of support workers. She is relaxed, confident and content with a full social life and is very much part of the community.'

If people with PMLD and their families are to take advantage of this initiative, there is a need for clear information and access to the support needed to achieve it, such as the work being done by Values Into Action.

Communication and equipment

As already stated (p.6 Choice), the communication needs of children and adults with PMLD are complex. It also needs to be understood that whilst some people with PMLD will clearly benefit from the use of technology, there are many for whom it will prove too challenging. It is an important strand of the work needed in the area of communication for people with PMLD, but not a total solution.

It is important to encourage the development of any technology, which may support the communication of children and adults with PMLD. But the equipment is only ever as good as the team of people supporting the individual to use it.

There are many people with disabilities who have the potential to learn how to use electronic communication equipment, but few are given the opportunity. Acquiring the skills to use a high-tech system can take months or years of extremely hard work. It requires the individual, his/her supporters in all environments and specialist healthcare professionals to work together and sustain motivation and a consistent approach.

Technology is never a replacement for basic yet fundamental changes that supporters can make to everyday communication. Communication skills are central to achieving real participation and it is essential that this area is given high priority for any individual with PMLD.

It should also be noted that children and adults with PMLD often have complex physical disabilities and that these can mask intellectual abilities. This is one reason that those working with such children and adults need to proceed on the assumption that any individual may be able to make use of communication technology.

Example

Danny is 29 years old and has cerebral palsy, which affects his mobility and ability to control his upper limb and head movement. He uses a wheelchair and requires support in all aspects of his life.

Until three years ago Danny's only method of expressing himself had been through facial expression, vocalising and a somewhat haphazard yes/no response using one blink for 'yes' and two for 'no'. Everyone involved in Danny's life had always felt that he should have been able to use a communication aid. However, the difficulties he experienced in controlling his limbs and his many involuntary movements had meant that no one had ever been able to establish a method of assessing his level of understanding and therefore, never attempted to introduce such a system.

Three years on, Danny now uses a fairly sophisticated electronic speech output aid which allows him to express needs, wishes, opinions, emotions and social language. This would not have been possible without the following assurances:

- A consistent and cohesive staff team at home and day service
- A regular team of health professionals with expertise in working with people with PMLD
- A positive attitude from all involved and the ability to problem solve
- A detailed plan for implementing the aid
- Signed agreements from all involved of their commitment to using the aid and to changing the way in which they communicated with Danny so that he had as many opportunities as possible to use his aid (i.e. not resorting to the yes/no questions)
- Regular meetings to review the implementation plan, to share information and to iron out any problems
- A method of daily communication between all on progress

This type of communication aid would only meet the cognitive needs of some children and adults with PMLD. However, it is felt that no communication aid (whether that be objects of reference, communication passports etc) would ever prove to be truly functional without the consistent and detailed approach outlined above.

Recommendation

- Further funding should be given to citizen advocacy schemes to ensure that people with PMLD have access to an advocate.
- Agencies should be required to have communication plans, which focus on meeting individual needs.
- People with PMLD should be given priority for person centred planning.
- Those responsible for policy development should ensure that they take account of the needs of people with PMLD.

Chapter 5: Supporting carers

Problems and challenges

The needs of parents and carers have been recognised to a certain extent in Valuing People. The role of parents of children and adults with PMLD is of particular significance because of the intensity and specialised nature of those caring responsibilities.

Research has shown that the number and range of daily care responsibilities undertaken by families is wide and daunting, such as the fact that, on average, they spend eight and a half hours per day in activities such as physical management (lifting, handling and positioning), basic care activities (dressing, bathing, toileting and assistance at mealtimes) and, in some cases, management of medical conditions like epilepsy (Hogg & Lambe 1988). This has remained one of the few substantial pieces of research that has focused on the needs of the parents of children and adults with PMLD. However, it is apparent that there has been little improvement in the support given to these families in the last 13 years.

A recent Mencap survey found that the combined time spent on basic care needs, educational and therapeutic needs and entertaining or simply being with individuals who could not be left unattended, was an average of 18 hours a day. In addition parents were woken an average of three times per night. Many families felt that they are very poorly supported by services and felt that their role and in-depth knowledge is not valued by professionals ('No Ordinary Life', Mencap 2001).

In addition, many families reported that they could not make use of the services offered, as service providers have failed to overcome a range of issues that have become barriers to using services, such as invasive care needs and lifting and handling regulations. It is simply not good enough to offer families services such as a home sitting service that has a 'no lifting policy' or that cannot administer rectal diazepam.

There appears to be a limited understanding of the kind of holistic family support needed. Further, in developing initiatives, which clearly benefit their more able peer group, services have failed to take account of the particular impact on people with PMLD and their families. By not doing so, they may be further disadvantaged. An example of this may be seen within the programme aimed at modernising day services. Some new models exclude a resource centre or base from which to operate and do not offer a full week's

timetable. It is not reasonable to expect parents either to use their own home as a base or to fill in vacant parts of the week by providing the care themselves. The caring task they already have is huge. 25-year-olds do not usually spend their days relying on the support of their parents, so why should people with PMLD?

Example

Jennifer is 42 with profound and multiple learning disabilities. She lives at home with her parents who are now in their 70s. Jennifer uses a wheelchair and has severe epilepsy and this means that there are lifting and handling issues, as well as the need to administer rectal diazepam should she go in to status epilepticus. A respite carer has been provided by social services but, following a risk assessment, it has been stated that this worker cannot do any lifting as Jennifer needs two people to lift her and they do not have enough resources to send two workers. She is not trained to administer rectal diazepam. She can only sit with Jennifer and so her parents cannot leave the house.

It is hard to imagine how these families sustain these levels of care day after day, night after night, without practical hands-on help from services. There is a need to prioritise the practical and emotional needs of such families and to identify more effective means of support.

Recommendations

- The needs of family carers should be identified as a priority.
- Family carers should have access to home based and/or residential short break services to support them in their caring role.

Chapter 6: Improving health for people with learning disabilities

Problems and challenges

Health is a particularly significant area for children and adults with PMLD, many of whom have complex health needs. There appear to be great difficulties in meeting a range of specialist and general health needs. Many parents describe the difficulties they experience in enabling their sons and daughters to access basic medical care:

‘My daughters are considered totally worthless. They are not treated like normal people. They cannot even get access to hospital treatment, not even basic nursing care...’ (Parent)

Various studies of the health needs of children and adults with PMLD demonstrate a high prevalence of severely underweight individuals, a higher prevalence of epilepsy, a high risk of pressure sores, a disproportionate amount of respiratory infection and a generally higher level of health care needed (Hutchinson 1988). In contrast, health care has been reported as poor. In one study of a group of people with PMLD who were given a health check, 92% were found to have a previously undetected but treatable condition (Meehan 1995).

There are also some services that people with PMLD have very little access to at all - in particular, mental health services. These are another example of how we accept the demeanour and behaviour of someone with PMLD as part of their overall disability and fail to recognise the signals they are giving us that something is not right. The mental health needs of young people with profound and multiple learning disabilities will be included in ‘The enquiry into meeting the mental health needs of young people’ led by the Foundation for People with Learning Disabilities (October 2001).

Intensive health care support

Children and adults with PMLD will require specialist support at various times. One example of a key health issue is swallowing disorders. These can cause malnutrition, dehydration and pneumonia as well as triggering associated health risks, such as susceptibility to infections, difficulties with wound healing and impairment to mental and physical function. People with swallowing disorders require access to specialist health professionals

and assessments, including a videofluoroscopy and interventions ranging from thickeners for drinks to gastrostomies.

Whilst we must be careful not to over-medicalise their needs, we must ensure access to high quality specialist health services when they are needed.

Health checks and addressing inequalities in health care

It would be very beneficial for people with PMLD to have access to regular health screening. Establishing the 'norm' for someone with PMLD, which can be complex in itself, will provide an important baseline in understanding the often subtle changes indicating the need for further investigation. Self-injuring behaviour, loss of appetite or a decrease in interaction for example, may all be vital pieces of information indicating a change in physical or emotional well being. The role of the proposed health facilitators could be extremely useful here.

Recommendations

- Children and adults with PMLD should have annual health checks.
- Children and adults with PMLD should be given priority in establishing the use of health facilitators.

Chapter 7: Housing, fulfilling lives and employment

Housing

People with PMLD can benefit from the full range of housing options when re-provisioning plans are developed. There is increasing expertise in this area, such as the housing advice given by the organisation 'Housing Options'. The following example illustrates their work:

Example

Rebecca is a young woman in her late 20's. She has profound and multiple learning disabilities (PMLD) and severe epilepsy. She was living in a large registered care home. It was an out of county placement, as her local authority considered her to be 'too disabled for them to provide for her care needs'. She was unhappy, sometimes wheeling herself into the corner of the room and scratching herself. Her parents were unhappy and wanted to do something better. The home she was in was due to close so something had to happen. Her father had just retired and dedicated himself to finding something different and it took several years before she arrived at her current situation.

Rebecca had a 'care assessment'. This concluded that Rebecca was unhappy and that she needed high levels of care and support. Her need to live with fewer people was raised as an option. Her parents decided that they would like Rebecca to have her own home and wrote to a housing association. The HA put together a bid for a bungalow but it was rejected as 'poor value for money'. A second bid was made for 'shared ownership'. In this option the HA is usually the partner. In grant terms, this is cheaper and at last the bid became 'good value'. The bungalow was built specifically for her needs. All facilities are fully accessible. It is the first time that Rebecca has been allowed in the kitchen! There are doors to the patio and a garden, a big bedroom with an en-suite bathroom and a 'drive in' shower. There are 3 bedrooms. She needs 24-hour care so one bedroom is for care staff and the third is a laundry. The house is next door to her parents. They can see her every day and, in effect, supervise the care. Recently the parents have set up a small company and employ the 6-7 staff needed themselves. The cost to the LA is the same as it was when Rebecca was at the out of county residential service, about £1,200 per week. (King 1988)

Those responsible for housing needs will often quote the cost, as well as the fragility, vulnerability and high support needs of people with PMLD as reasons not to consider more options.

This case study demonstrates the possibilities for a very profoundly disabled person to live in their own home without a huge increase in cost but, enjoying a huge increase in their quality of life. This is demonstrated by things like a significant improvement in communication skills.

However, these examples are very much in the minority and have often only come about because of determined parents. One account is given by Jean Wilson and Pat Fitton who wanted their daughters to have a home of their own. It tells of the difficulties they had to overcome to achieve this finally (Fitton, O'Brien and Wilson 1995). These accounts are inspiring but for many parents, who may be desperately tired after years of caring, they appear beyond reach.

Modernising day services

The White Paper recognises that there is a need to think very carefully about day services for people with PMLD.

There is much that people with PMLD can take part in within a community setting. There is also a strong need to increase their participation in community life. Some activities do not have to be provided within a special setting. A market, shopping centre or café can provide a stimulating multi-sensory experience for some people. However, many people with PMLD need specialised activities, such as daily physiotherapy or a hydrotherapy pool, rather than the local leisure centre's pool.

The closure of larger day centres and the move to more community based smaller centres has frequently had a substantial and negative impact on people with PMLD. There has been less contact with more able people with a learning disability (and a correspondingly less stimulating environment), an increase in segregation and a decline in the range and quality of activities.

This is largely because many service providers have not taken on board some of the additional needs of people with PMLD such as lifting and handling, health needs, and special forms of transport, and have allocated insufficient resources to enable them to take part in community-based opportunities. For example, there are currently very few facilities in the community that have adult sized changing areas. This means that some form of building based service may be needed.

There is no reason why people with PMLD should not enjoy real activities in the community and build their own circle of friends. But for this to happen, services must address the resource issues, staff skills and the practical challenges of meeting diverse needs in an imaginative way. If they fail to do so there is a high risk that people with PMLD will become increasingly excluded from a crucial service.

Recommendations

- The modernisation of day services programme should be planned, monitored and evaluated with the needs of people with PMLD in mind.

Chapter 8: Quality services

People with additional and complex needs

This section of the White Paper conveys some understanding of the range of needs that have to be addressed and the array of services that need to be able to respond. These services must be able to provide the very specialist skills required for a significant improvement in the quality of support.

There is a shortage of therapists in general, particularly those with the expertise needed for children and adults with PMLD. Historically, many services have not prioritised people with PMLD against the competing demands of their more able peer group. There is a culture of under-investing in people with PMLD and in those responsible for their care.

All staff need to have access to training that addresses the specific needs of people with PMLD. Failing to support staff in gaining the skills they need results in people with PMLD typically and routinely receiving less attention and support from staff than those with more moderate needs.

Staff turnover is high in services for people with PMLD, often reflecting the feeling of helplessness and perceived lack of feedback. This is a direct result of the lack of appropriate staff training. Staff working with children and adults with PMLD need to be trained in specialised skills such as effective communication strategies, multi-sensory approaches and Intensive Interaction (Nind and Hewett 2001).

Recommendations

- Health professionals should receive additional training to ensure that people with PMLD have equal access to the services they provide.
- Induction training for care staff should include information on the needs of children and adults with PMLD.
- Staff working directly with children and adults with PMLD should have access to high quality training, in particular, communication skills training.

Chapter 9: Making change happen

It is significant that there are no specific objectives for people with PMLD within this final section. It is also clear that if children and adults with PMLD are to benefit from the initiatives set out in the White Paper, there are implications affecting resources.

In putting forward a range of views, examples and ideas, the PMLD Network has attempted to illustrate the overall point that children and adults with PMLD are amongst the most excluded people in our society. Unless we focus our attention on their particular needs in a comprehensive and holistic way, they are in danger of remaining so.

‘Perhaps the single biggest barrier lies in our low expectations and failures of imagination.’ (Steve Beyer 2000)

Overall, the task is to develop our understanding of the needs of children and adults with PMLD and to design services that are truly inclusive of their particular needs. Only then will we be able to respond to the challenge of ‘enabling extraordinary people to live ordinary lives.’ (McConkey 1998)

A vision for the future: Katy and Gemma’s story

Gemma (23) and her friend Katy (22) have profound and multiple learning disabilities. Neither Gemma nor Katy has any spoken language and Gemma uses a wheelchair. Katy has serious eating problems and until recently was very underweight. Gemma’s mother, Jan and Katy’s mother, Wendy, who had been friends since the girls started school together, began to look to the future in terms of residential care.

As they began to consider the various residential options available to them, they became very concerned and depressed because there was very little on offer. The options were far away from home and none seemed able to offer anything like their current home lives.

In desperation, Wendy and Jan decided to get together and write a vision for their daughters’ happiness. They didn’t know it at the time, but what they produced was very much like a person centred plan. This vision formed the basis of a comprehensive booklet detailing the exact level of support they needed and how it should be provided. It also set out the two main objectives of finding a suitable bungalow and arranging for its purchase and secondly obtaining the funding for the support. They presented the document to the local social services department in Oxfordshire. It was well

received, but the story of how their vision was eventually achieved is a long one with Wendy and Jan having to overcome many hurdles before realising the dream, after more than two years of intense negotiation.

However, Gemma and Katy are now tenants of a large bungalow, re-designed inside from two small adjoining properties. They have a circle of support, the members of which are trustees of a Supported Living Trust. This ensures that Gemma and Katy's wishes and choices remain central to any decisions made and that their direct payments are used to best advantage on their behalf.

Gemma and Katy have been living in their home for over two years now and they are both happy and flourishing. They have a team of seven staff, including a team leader and together they form a very cohesive group. Gemma's mum still does an occasional shift at the home when needed and both women stay with their families regularly. Gemma and Katy now have Essential Life-style Plans, which are updated regularly ensuring they continue to lead the lives they choose.

'As a parent, it is wonderful to be able to visit my daughter whenever I want and feel completely at ease and welcome. I am absolutely confident that our daughters are having the best life that they could possibly lead surrounded by people who care about them as individuals - and with the sort of partnership we all enjoy, I feel sure it can only get better.' (Jan Roast, Gemma's mother)

Summary of recommendations

- 1) Clarity about terminology and definitions so that the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood.
- 2) The DOH should commission research into prevalence.
- 3) Local authorities should be required to audit, record and monitor the number of children and adults with PMLD.
- 4) The DOH National Survey should include children and adults with PMLD.
- 5) The needs of children and adults with PMLD should be moved further up the government agenda. There needs to be a champion of these issues who can focus on the inclusion of people with PMLD. There needs to be specific PMLD representation on the Learning Disability Task Force. A PMLD sub-group should be formed and represented on the task force. This sub-group would need to establish networks of agencies supporting children and adults with PMLD.
- 6) Partnership Boards should represent people with PMLD, as a matter of course.
- 7) People with PMLD need to be seen as a priority if they are to benefit from what additional money there is to effect change. Scarcity of resources must not be used to justify the argument that agencies should focus on the needs of the many, versus the few.
- 8) All agencies need to recognise that people with profound and multiple learning disabilities can make choices when given the right support.
- 9) Parents of children and young people with profound and multiple learning disabilities should have one key worker who supports them and co-ordinates service provision.
- 10) Further funding should be given to citizen advocacy schemes to ensure that people with PMLD have access to an advocate.
- 11) Agencies should be required to have communication plans, which focus on meeting individual needs.
- 12) People with PMLD should be given priority for person centred planning.
- 13) Those responsible for policy development should ensure that they take account of the needs of people with PMLD.

- 14) The needs of family carers of children and adults with PMLD should be identified as a priority.
- 15) Family carers should have access to home-based and/or residential short break services to support them in their caring role.
- 16) Children and adults with PMLD should have annual health checks
- 17) Children and adults with PMLD should be given priority in establishing the use of health facilitators.
- 18) The modernisation of day services programme should be planned, monitored and evaluated with the needs of people with PMLD in mind.
- 19) Health professionals should receive additional training to ensure that people with PMLD have equal access to the services they provide.
- 20) Induction training for care staff should include information on the needs of children and adults with PMLD.
- 21) Staff working directly with children and adults with PMLD should have access to high quality training, in particular, communication skills training.

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PMLD Network Membership List

Steve Carnaby	Lecturer in Learning Disability, Tizard Clinical Psychologist, Parkside NHS Trust
Beverley Dawkins	National Officer for Profound and Multiple Learning Disabilities, Mencap
Nadine Jay	Project Co-ordinator Circles Network, Credo Project
Wendy Lewington	National Advocacy Co-ordinator, Scope
Gudrun Limbrick	Trustee The Hansel Trust
Hazel Morgan	Head of the Foundation for People with Learning Disabilities
Jan Roast	Parent
Sarah Robertson	Resource for Opportunity and Change (ROC)
Judith Samuel	British Psychological Society Division of Clinical Psychology Special Interest Group (Learning Disability) Consultant Clinical Psychologist and Co-ordinator of the Multiple Disability Resource Team Oxfordshire's Learning Disability Trust
Laura Waite	Royal National Institute for the Blind

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