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A study to define: profound and multiple learning disabilities (PMLD)

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Abstract This study aimed to define the term 'profound and multiple learning disabilities' (PMLD). A shared understanding of terminology or diagnostic terms describing groups of individuals is important for the purposes of strategic development, service planning, and the provision and equity of service delivery. A literature review provided different definitions and meanings associated with the term. The meaning attributed to the definitions was explored in focus groups and individual interviews (face to face and telephone) with service managers, commissioners, practitioners, frontline healthcare staff and family carers who provide services, support and care for people with PMLD. Further iterative discussions were held with a smaller group over the precise wording of the chosen definition to ensure there was a shared and common understanding. Personal characteristics for the purpose of this study are defined as diagnoses, disabilities, impairments, activity restrictions and other characteristics which represent a person with PMLD.

Keywords definitions; PMLD; profound and multiple learning disabilities; service delivery

Background and literature review

The term 'profound and multiple learning disabilities' (PMLD) is now commonly used to describe a person with severe learning disabilities who

most likely has other complex disabilities and health conditions. Whilst the use of generic labels to ascribe a disabled identity to another has been criticized by social constructionists (e.g. McClimens, 2005), not least for the unequal power relations that manifest within health and social care systems, the authors do not propose that such labels are to be used gratuitously or to indicate lesser value. We make a distinction between service planning and service delivery, and in doing so we recognize that every collective identity is open to both internal subdivision and incorporation into some larger category of primary identity (Calhoun, 1994). Service delivery is person centred and based around an individual's aspirations, strengths and needs. In contrast, service planning requires collation and categorization of demographic health needs information, and it is here that the label of PMLD has currency. An agreed definition of terms used is essential to enable planning for the provision of appropriate and acceptable services to improve the quality of life for individuals throughout their life course. Despite its widespread usage there is no single universally agreed definition of the term PMLD. Whilst this omission persists, the proactive planning of health and social care remains a haphazard affair and there is a risk that future services will not have the capacity to meet the complex needs of all individuals with PMLD.

Valuing People Now (Department of Health, 2009) highlighted that commissioners and policy makers were not sufficiently addressing the needs of people who had more complex needs, including those with profound intellectual and multiple disabilities. *Raising Our Sights* calls for up-to-date information about the needs of people with PMLD:

> Recommendation 5: Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services. (Department of Health, 2010, para. 48).

There is clear evidence nationally of an increase in pressure on learning disabilities adult social care budgets (ADSS, 2005), which can to a large extent be attributed to increased numbers of children with major disabilities surviving into adulthood. Preliminary data from the Sheffield Learning Disabilities Case Register (Parrott et al., 2008) indicates that the overall number of people with severe or complex needs rose by 17 percent from 682 to 786 between 1998 and 2008. Over this 10 year period the number of 15- to 19-year-olds with severe or complex needs increased by 70 percent from 85 to 144. At the same time that demand for support is dramatically increasing, the existing service provision is being threatened with cuts (Williams, 2008). Williams highlights the need for a detailed

analysis of the numbers and needs of people with PMLD in order that rational planning can be carried out. The starting point for this is clarity about who constitutes the group of people who are categorized as having profound and multiple learning disabilities. The recommendations contained in the report *Raising Our Sights* rely upon this clarity to determine who is to be included within the group labelled as having 'profound intellectual and multiple disabilities' (Department of Health, 2010, para. 48).

In their paper 'Valuing People with Profound Multiple Learning Disabilities' (a response to the government White Paper *Valuing People*), the PMLD network state that:

> Clarity about terminology and definitions should be achieved so that the population of children and adults with PMLD can be counted, and more importantly their needs can be understood. (2002, p. 6)

Lack of clarity in the understanding of this terminology leads to confusion not only for families but also in service planning, access and provision, as well as problems with regard to equity. Definitions attributed to diagnostic or other terms can influence studies of epidemiology, the provision of benefits, and access to services.

In common with other services across the United Kingdom, the Joint Learning Disabilities Service (JLDS) in Sheffield (a partnership between Sheffield Health and Social Care NHS Foundation Trust (SHSC) and Sheffield City Council) has no commonly agreed definition or description of the personal characteristics which contribute to the decision to describe an individual as having PMLD with complex health needs and thus requiring certain levels of support and services.

Gittens and Rose (2007) note that one of the problems in identifying individuals with PMLD is the confusion and lack of a generally accepted definition for this population. Their audit of individuals with PMLD, in a West Midlands Community Health Trust catchment area, undertook a review of published definitions of PMLD in order to identify appropriate clients from data held on a special needs register. The definitions are highlighted below. Following their audit, Gittens and Rose (2007) adopted the Lacey (1998) and Hogg (2004) definitions of PMLD. However these definitions stress the service needs of individuals with PMLD and present a medical or deficit model of disability which has been criticized by disability scholars (e.g. Oliver, 1990), carers (e.g. Murray, 2000) and organizations representing the interests of disabled people (UPIAS, 1976). Definitions stressing the service needs of individuals are useful for service providers but are not necessarily acceptable to people with disabilities and their carers. To define the term to be used in the Joint Learning Disabilities

Service we consulted carers of people with PMLD along with commissioners and a range of service providers.

Methodology

Literature review

A literature search was undertaken in nine electronic databases that covered a range of disciplines; general health, mental and psychological health, allied health, social sciences, health policy and management and education. In addition, a number of websites of organizations likely to contain information on learning disabilities were browsed.

Focus groups and interviews

A series of individual telephone or face-to-face interviews and discussion groups[1] was conducted with representatives in regular contact with people with PMLD from the Joint Learning Disabilities Service (JLDS), the local authority and carers of individuals with PMLD. Carers were selected from the Sheffield Case Register using the ICD-10 diagnoses (World Health Organization, 2007) held on a central database by Sheffield City Council. Due to the sensitive nature of the topic, and rather than conducting telephone interviews with family carers, they were all interviewed on a face-to-face basis in their own homes. Ethical approval to conduct the study was obtained from the South Yorkshire Research Ethics Committee and honorary contracts were obtained from Sheffield City Council and Sheffield Health and Social Care NHS Foundation Trust.

Participants were each sent a covering letter and an information sheet outlining the study. They were then contacted by the researcher to allow for the opportunity to ask any further questions about the study and to decide whether or not to participate. Prior to each interview, informed consent was obtained. Based on the individual researcher definitions outlined in the literature review, a card sort exercise was utilized and participants were asked to rank their preferred definition and give their reasons for that choice. Participants were also asked for their views on both the organizational definitions of PMLD. Additional information was collected specifically from family carers using a short questionnaire on medical conditions, aids and services used by the service user or carer.

The chosen definition underwent further scrutiny to ensure its mutual and shared understanding by individuals from the different stakeholder groups. This required five iterations prior to common agreement.

Findings

Literature review

The definitions ascribed to people with PMLD are grouped as being developed by researchers and by organizations. The definitions that have been adopted are diverse and incorporate a range of elements. Most have some characteristics in common, including:

- profound cognitive impairment, and social functioning, as well as
- more than one additional disability, usually including sensory or physical impairment, and may also include
- autism or mental illness or challenging behaviours or an associated medical factor.

In addition some definitions attempt to quantify the extent of the impairment, and others include details about the person's support needs to achieve everyday outcomes.

PMLD definitions

Researcher definitions

Lacey (1998, Introduction, p. ix)

> [Profound and multiple learning disabilities] . . . has more than one disability and . . . one of these is profound intellectual impairment. Often the multiplicity of disabilities includes sensory or physical impairment but others may be involved, such as autism or mental illness. Behaviour which may be very challenging and/or self injurious may also be present.

Ware (1996, Introduction, p. iv)

> [Profound and multiple learning difficulties] . . . we mean that their degree of learning difficulty is so severe that they are functioning at a developmental level of two years or less (in practice, often well under one year) and also they have one or more other severe impairments, for example they may be unable to walk, be severely visually impaired, or both.

Samuel and Pritchard (2001, p. 39)

> [Profound learning disability] . . . 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 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 individualized relationship with a carer, people with profound learning disabilities have the chance to engage in their world and to achieve their

optimum potential (which might even mean progress out of this classification as development proceeds). However, without structure and appropriate one-to-one support such progress is unlikely.

Hogg (2004)

[Profound intellectual disability and complex health care needs] ... individuals whose developmental abilities fall within those characterizing the first 18–24 months of typical development, and for whom communication is typically non-verbal (though some will have limited one and two word utterances). In addition to their intellectual disability they have physical and/or sensory impairments that significantly limit adaptive behaviour. There is also a high probability of epilepsy, dysphagia and/or respiratory problems. Health care presents significant challenges to professionals and family carers.

Ware (2004, p. 176)

[Profound and multiple learning disabilities] ... have a profound cognitive impairment/learning difficulty, leading to significant delay in reaching developmental milestones. Such learners will be operating overall at a very early developmental level and will display at least one or more of the following:

- Significant sensory impairments
- Complex health care needs/dependence on technology
- Significant motor impairments.

Organizational definitions *PMLD Network*. The PMLD Network has developed a definition for PMLD. In their 'easy-read' version of the fact sheet (available at http://www.pmldnetwork.org/) they state that:

People with profound and multiple learning disabilities have more than one disability.

Their main disability is a profound learning disability. This means they need lots of support.

They might have these other disabilities as well.

- Physical disabilities. This is a disability to do with the body.
- People who use a wheelchair have a physical disability.
- Sensory disabilities. This is when people find it difficult to see or hear.
- Lots of health problems.
- Mental health problems.
- Autism.
- People with profound and multiple learning disabilities need a lot of support. They also find it very difficult to communicate.

A more detailed [standard] version of this document is available at http://www.pmldnetwork.org/.

Welsh Assembly Government. In their 'Assessment Materials for Learners with Profound Learning Difficulties and Additional Disabilities' guidance document, the Welsh Assembly Government (2006) provides the following definition for PMLD in Appendix 1 (p. 51):

> Who are learners with PMLD/complex needs?
>
> This working definition of learners with profound and multiple learning difficulties was compiled by a General Teaching Council for Wales network group to guide their discussions and enable them to plan appropriate outcomes for the aspects of the Personal and Social Education (PSE) Framework. The dangers of labelling learners are recognised and flexibility is required to avoid limiting expectations. Learners with PMLD will have a profound cognitive impairment/learning difficulty, leading to significant delay in reaching developmental milestones. Such learners will be operating overall at a very early developmental level and will display at least one or more of the following:
>
> - Significant motor impairments
> - Significant sensory impairments
> - Complex health care needs/dependence on technology.
>
> The inter-relationship of these disabilities increases the complexity of need, in turn affecting all areas of learning.
>
> Learners with PMLD will have a Statement of Special Educational Needs (Special Educational Needs and Disability Act 2001) and are likely to be working on the behaviours shown on the route map for most or all of their school life. Staff will almost certainly find it difficult to establish reliable and consistent methods of communicating with them. Moreover, owing to high levels of dependency for basic self-care (such as dressing, toileting and feeding), they are also likely to require extra resources in school such as:
>
> - Specialist staffing and substantial support
> - Adapted curriculum and Individual Educational Plans
> - Mobility aids and therapy programmes
> - Frequent assistance and medical support.

Every Child Matters: Change for Children. On the *Every Child Matters, Change for Children* website (http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/glossary/) the following definition is provided in the glossary of terms:

> Children with profound and multiple learning difficulties have complex learning needs. In addition to very severe learning difficulties, the children will have other significant difficulties, such as physical disabilities, sensory impairment or a severe medical condition.
>
> They require a high level of adult support, for their personal care as well as for their learning needs. They are likely to need sensory stimulation and a

curriculum that is broken down into very small steps. Some children with profound and multiple learning difficulties communicate by gesture, eye pointing or symbols; others communicate by using very simple language.

Raising Our Sights (Department of Health, 2010). Following the publication of *Valuing People Now* (Department of Health, 2009), Professor Jim Mansell was asked to review services for those with profound and multiple learning difficulty. The definition he used to inform this work was:

> People with profound intellectual and multiple disabilities are among the most disabled individuals in our community. They have a profound intellectual disability, which means that their intelligence quotient is estimated to be under 20 and therefore that they have severely limited understanding. In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury.

World Health Organization (2007). WHO provides a definition for 'profound mental retardation' as:

> IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility.

Findings from focus groups and interviews

Healthcare professionals subgroup Seven healthcare professionals were interviewed in this category. Participants had varied professional disciplines including speech and language therapists (n = 3), nurses registered with the Nursing and Midwifery Council (NMC) on the learning disabilities register (n = 2), clinical psychologists (n = 1) and occupational therapists (n = 1). Two individuals took part in a discussion group and the remaining five participated in a telephone interview. Four participants favoured the definition provided by Samuel and Pritchard (2001) and the remaining three participants expressed the view that Ware's (2004) definition was their preferred choice. The rationale for those decisions is highlighted in some of the summaries and verbatim quotes highlighted below:

Samuel and Pritchard (2001)

> I didn't like the little or no symbolic interaction or no apparent understanding of verbal language . . . we need to look at communication in a wider sense

> rather than just focusing on language ... it's a definition which also recognizes that people can achieve things.

> It's quite detailed and gives space to what's possible ... it's a strengths approach ... it brings out what is needed for someone with PMLD to engage in the world and in terms of funding, the last sentence in that statement is important.

Ware (2004)

> It [definition] recognizes the cognitive impairment/learning disability first and foremost.

Whilst some participants acknowledged the view that they did not feel comfortable about developmental norms in relation to age, 'as a definition, it sits more comfortably with me'. Others commented on the fact that 'as a definition, it gives much more clarity'.

Frontline care staff A total of five frontline care staff took part in the study via a telephone interview. Participants worked in day care services for individuals with PMLD and described their occupational backgrounds as communication development worker ($n = 2$), social inclusion coordinator ($n = 1$) and day care worker ($n = 2$). Two participants favoured the definition provided by Ware (2004) and two preferred the definition provided by Hogg (2004). The remaining participant expressed the view that Lacey (1998) was an ideal definition of PMLD which represented his experiences of working with a PMLD client group in day care services. Participants' justifications for opting for particular PMLD definitions are highlighted as follows.

Ware (2004)

> It's a clear definition but a dependence on technology? Who has the dependence – the client or the healthcare staff?'

The idea of technological dependence was a facet of this definition which was highlighted as problematic by another participant in the same subgroup and, as a result, was not considered a fundamental aspect of PMLD:

> I don't know whether it's too brief. The dependence on technology? Technology might help but I wouldn't say that they have a dependence on it. It doesn't really define it for me.

Hogg (2004)

> It's still wordy but it seems clearer. I like the comments about non verbal communication ... it's not all about language. It covers some of the major health problems like epilepsy and swallowing difficulties which are both prevalent and important.

Lacey (1998)

> It [definition] relates to my practice but there's no self injurious behaviour, no autism or no mental health problems . . . autism can be difficult to establish if there's no communication.

In spite of selecting Lacey (1998) as his preferred definition of PMLD, the above participant contended that mental illness and autism should not be considered characteristic features of a definition of PMLD. This approach suffused the views of the majority of participants across the various subgroups. That autism, mental health problems and self-injurious behaviour were distinctive features of a definition of PMLD were viewed as problematic by the majority of participants. As two participants in the same subgroup of staff commented:

> I don't agree with the point about mental illness. It's not necessarily a facet of PMLD that I've come across.
>
> Self injurious behaviour is not a feature that has anything to do with PMLD.

Likewise, another healthcare professional commented:

> Autism and mental illness are not the defining characteristics of PMLD and should not be incorporated into any definition of PMLD.

Carers of individuals with PMLD Eight participants caring for family members with PMLD were interviewed in this subgroup. Four individuals took part in a joint interview as husband and wife. Seven out of the eight family carers favoured the definition put forward by Samuel and Pritchard (2001). The remaining family carer expressed the view that whilst it 'wasn't perfect', Ware's (2004) definition was preferable. Their views are expanded upon in the following verbatim quotations. These highlight that any definition of PMLD which is in line with consumer opinion should make explicit both the importance and the value of interpersonal relationships with significant others (including family and care staff).

Ware (2004)

> I agree with that one [definition]. That one is my son – it certainly fits my son . . . it's not perfect but I could accept that one.

Samuel and Pritchard (2001)

> That one [definition] is Robert . . . all of it. It describes him more.
>
> I liked the last sentence a lot. It's more in-depth.
>
> The last sentence is a nice positive spin. Each person has their own special quality.

At the same time, participants in this and other subgroups interviewed for this study disagreed with the point put forward by Samuel and Pritchard (2001) that there was 'little or no apparent understanding in relation to verbal language'. These views are highlighted in the following two excerpts taken from interviews with family carers:

> [son] brings me a cup if he wants a drink, bites his hand if he's upset – particularly if the grandchildren are in the room and they're making too much noise.

> [son] can understand language so I don't agree with that.

Stressing the fundamental place of language in society, participants across all subgroups articulated the opinion that whilst language was the prevailing means by which we communicate, other forms of communication need to be taken into account and, as a result, a working definition of PMLD should stress this – particularly the importance of eye contact and body language, for example. This was elaborated upon by another participant from the healthcare professional subgroup involved in teaching intensive interaction to frontline care staff who argued that:

> Language is by no means the only method of communication for individuals with PMLD and I've spent lots of time working with frontline care staff to make them realize that.

The same participant, reviewing his own position with regard to an acceptable definition of PMLD, appraises the Samuel and Pritchard (2001) definition from the point of view of family carers and, whilst it does not concur with his own point of view, argues that:

> There's nothing measurable in terms of a service provision perspective and [it's] vague from a clinical perspective. There's nothing objective. But, from a carer's point of view, this definition may work better because it focuses on their care needs.

Managers of services Three service managers took part in a telephone interview. They described their professional roles as health facilitation co-ordinator ($n = 1$), day care manager ($n = 1$) and developmental manager ($n = 1$). Those who took part in a telephone interview all favoured the definition put forward by Samuel and Pritchard (2001). Whilst one manager contended that the definition was not 'ideal', on the whole, it was seen to be a more balanced definition which did not focus too heavily upon physical disability and the body, which to varying degrees they claimed the others did:

> It's [definition] quite a good one because it gives a good picture and it's quite balanced at the end . . . it's a positive definition.

> It's quite person centred as a definition.

> It [definition] gives you a good understanding. I like the last bit of that definition.

> It [definition] puts the social context into perspective as well as language which is important.

> The primary stuff is more about language and interaction. It's not ideal but the closing statement around individualized relationships is better. The one to one is everything to people with PMLD.

One manager commenting on the definition expressed the view:

> The people bit needs to come back to the top. We need a general value based statement and something which takes social engagement as primary.

Discussion and conclusion

Of the 23 participants in this study, 14 (60%) favoured the definition put forward by Samuel and Pritchard (2001). It is noteworthy that seven of the eight carers (87.5%) chose this definition. Whilst many participants conceded that no definition can fully articulate the complexities associated with PMLD, and that there can be issues associated with labelling (although in some cases the effects can be positive as well as negative), the definition focuses less upon physical difficulties such as epilepsy and dysphagia and how that can influence people's thinking about an individual's cognitive ability. Instead it highlights the circumstances which are necessary to enable individuals with PMLD to be given the opportunity to participate in their immediate situation, their community and ultimately in wider society. It was felt that whilst physical disabilities coexist with cognitive impairment, the former did not take precedence. Indeed, many participants expressed the view that healthcare needs were not necessary 'complex' enough to warrant a dependence on technology – a view expressed by Ware (2004). Moreover, participants across the range of subgroups disputed the idea put forward by Samuel and Pritchard (2001) that an individual with PMLD had 'little or no apparent understanding in relation to verbal language'. Rather, they expressed the view that non-verbal communication frequently took precedence and it was a case of developing a good interpersonal relationship with an individual with PMLD in order to understand their individual method of communication. On the whole, it was felt that the definition provided by Samuel and Pritchard (2001) was better on the basis that it was predicated on more of a strengths model, that it recognized individuality, and that there was more of an emphasis upon developing rapport and trust and providing services for the

individual within the context of their needs and wants in an effort to increase their quality of life.

Improving upon the Samuel and Pritchard definition to ensure that it covered the range of issues identified in the interviews and focus groups and to improve clarity took a further five iterations. This iterative development was primarily conducted through e-mail and telephone discussion. Interested representatives of the different stakeholder groups were involved.

The agreed definition which will be adopted by the Joint Learning Disability Service in Sheffield is:

> People with profound and multiple learning disability (PMLD):
>
> - have extremely delayed intellectual and social functioning
> - may have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures)
> - often require those who are familiar with them to interpret their communication intent
> - frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments.
>
> They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualized relationship with a carer.

This definition is now being used across services in Sheffield. Information is collated from as many different sources as possible including interviews with family members and carers, health and education records and the opinions and assessments of members of the multidisciplinary team, and a decision is made to determine whether or not it is appropriate and helpful to describe someone as having PMLD. Having defined the relevant population, it is possible to develop a strategic framework to identify the needs of the group of people that fall within this definition, and to plan services for them and their carers that will achieve the aims outlined in *Valuing People* (Department of Health, 2001) and *Raising Our Sights* (Department of Health, 2010). By defining the group of people who are considered to have PMLD, it will be possible to use the Sheffield Learning Disabilities Case Register (Parrott et al., 2008) to identify the individuals who are to be addressed by the Sheffield PMLD strategy and to subsequently evaluate its impact by reviewing the outcomes for this defined group.

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Notes

1 Due to difficulties experienced with arranging discussion groups, the majority of staff groups were interviewed over the telephone. Carers of individuals with PMLD were interviewed face to face.

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