Supporting people with profound and multiple learning disabilities

CORE & ESSENTIAL SERVICE STANDARDS

COVER ILLUSTRATION: NIKI DOUKA

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Contents

Foreword 7

Supporting statements and endorsements 9

Introduction 11

Why have we developed the Core & Essential Service Standards? 11

Towards a working definition of profound and multiple learning disabilities (PMLD) 12

People with PMLD – descriptions and numbers 12

Aims of the Standards 15

Who are the Standards aimed at? 16

How to use the standards? 18

Core & Essential Service Standards

Organisations 20

Standard 1: Leadership 20

Standard 2: Quality 21

Standard 3: Staff development (skills and confidence) 22

Standard 4: Physical Environment 23

Standard 5: Communication 24

Standard 6: Health and Wellbeing 25

Standard 7: Social, Community and Family Life 26

Individuals 28

Standard 1: Communication 28

Standard 2: Health and Wellbeing 30

Standard 3: Meaningful/Quality Relationships 32

Standard 4: Social and Community Life 33

Standard 5: Meaningful Time 33

Standard 6: Transitions 34

Acknowledgements 36

Further reading 37

Resources 38

"A person's ability to communicate is not dependent on their being able to master certain skills, it is dependent on our ability to listen and communicate responsively"

Jo Grace, The Sensory Projects

Foreword

The Core and Essential Service Standards are designed to improve the lives and life experiences of people with profound and multiple learning disabilities.

It was felt that time and effort was required to bring profound and multiple learning disability provision in line with initiatives implemented to improve the lives of people with learning disabilities and autism, who present with 'behaviours which challenge'.

In terms of population, this group of children, young people and adults are small in number, often isolated and marginalised. Indeed, in terms of policy, this is a group that is often forgotten or considered as an afterthought. Professor Jim Mansell, sadly deceased, in his 'Raising our Sights' Report of 2010 found that families of people with profound and multiple learning disabilities often had to struggle to get the services and support they need, that this group of people faced discrimination, prejudice, and low expectations. Seven years on and little has altered in terms of policy and life experiences for this group and their families.

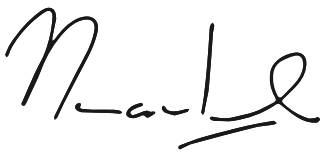
Developed by a diverse group of family members, education/health/social care professionals and academics these Service Standards are the result of a positive and passionate desire to ensure people with profound and multiple learning disabilities, regardless of age and circumstance receive excellent support and services consistently and are always respected as a person. While reflecting on the inadequacy of focus for this group through national policy, it is the intention of the people who developed these Standards to focus on the future with positivity and a commitment to work in unison to constantly drive up standards.

The Core and Essential Service Standards are designed to create a means for Commissioners of education, health and social care to work closely in partnership with service providers to ensure the best possible outcomes for people being supported. Through Commissioners and providers having shared expectations and standards of service delivery I can ensure that wherever a person lives, they can expect similarly high standards.

I urge that Commissioners use the Core and Essential Standards when purchasing education, health and social care services, when developing their service specifications and in collaborative engagement with service providers and families to enhance future provision. Equally I strongly urge service providers to use the Service Standards to regularly review the services they provide, evidence the quality of their provision and work to continually enhance support and services for people with profound and multiple learning disabilities.

I look forward to improved local and national networking and a strong, raised profile of people with profound and multiple learning disabilities, highlighting personal success stories and an emphasis on positive outcomes.

Rt Hon Norman Lamb MP



Supporting statements and endorsements

NHS England

There has been increased understanding of and efforts to improve the lives of people with a learning disability and address the inequalities experienced by this group of people over recent years. Progress has been made but there is still a way to go.

In NHS England's Learning Disability programme, we have seen much improved data about health inequalities, that have informed policies, guidance and actions in relation to issues such as: Transforming Care for people who display behaviours that challenge others, stopping the overmedication of people with a learning disability, autism or both (STOMP), and work to improve the health outcomes for people such as Annual Health Checks. These initiatives are aimed at all people with a learning disability but they do not explicitly focus on the strengths, needs and ambitions of people with profound and multiple learning disabilities and those who love, care for and support them.

A whole-system response is the key to delivering high quality services and support for people. For this to be a reality, services need to demonstrate a strong commitment to a shared value base which places individuals and their quality of life at the heart of all they do. Care and support should then be delivered with the aim of improving the person's quality of life. In order for this to be successful, it will require collaborative, multi-disciplinary and multi-agency working, as well as skilled informed responses from health and social care services, in partnership with the person, family, and those who provide day-to-day support.

We welcome this document which provides an informative and practical resource to enable those who commission services for, as well as for those who support, people with a profound and multiple learning disability, children and adults, to ensure access to consistent high-quality support throughout their lives, when supported by any service provider.

Kevin Elliott; Clinical Lead, Improving Health & Quality, Learning Disability Programme, NHS England

Royal College of Occupational Therapists

As this document recognises, there is a considerable need for guidance and standards focusing specifically on individuals with profound and multiple learning disabilities (PMLD). There is a need for collaborative service provision and commissioning , working across organisational boundaries to support those with PMLD, addressing the needs and aspirations of individuals, their families and carers.

Occupational therapists believe the opportunity to participate in a meaningful way within everyday life is a fundamental human right; for individuals with PMLD, additional support from others will be required to understand preferences and determine how meaningful participation can be facilitated and supported.

We therefore welcome and endorse these standards as a tool for service users, commissioners, professionals, (including occupational therapists and their colleagues in health, social care and education) to ensure that the needs of those with PMLD with respect to health, wellbeing and participation are met by high quality, coordinated services.

Karin Bishop; Assistant Director Professional Practice,
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Introduction

Why have we developed the Core & Essential Service Standards?

People with profound and multiple learning disabilities (PMLD), by the very nature of their personal barriers to advocate for themselves, require their families/carers/advocates/friends and involved professionals to advocate for them.

A group of like-minded advocates for people with profound and multiple learning disabilities came together several times in 2016, in order to identify a means of ensuring a stronger voice for people, at a national level, and to aim to ensure that people received good quality service and support regardless of where they lived and who was providing their support.

Professor Jim Mansell, in his review of services for adults with profound intellectual and multiple disabilities noted that 'commissioners and policy makers were not sufficiently addressing the needs of people with learning disabilities who had more complex needs, including people with profound intellectual and multiple disabilities' (Mansell, 2010).

Seven years later the same can be said to be true. In light of abuse scandals such as 'Winterbourne View', the Transforming Care Agenda has ensured a concentrated effort by NHS England, the Association of Adult Social Services (ADASS), the Care Quality Commission (CQC), Local Government Association (LGA), Health Education England (HEE) and the Department of Health (DH) to improve services and support for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services. The needs of people with profound and multiple learning disabilities do not receive the same explicit reference in policy and initiatives.

This newly formed collective of advocates for people with profound and multiple learning disabilities (see details of all contributors at the end of this document), are clear that there is a lack of focus on the needs of this group of people and an absence of strong networking. Hence the drive to develop and embed these standards.

Towards a working definition of profound and multiple learning disabilities (PMLD)

People with PMLD – descriptions and numbers

The term *profound and multiple learning disabilities* (PMLD) is a description rather than a clinical diagnosis. Whilst there is no definitive set of characteristics for PMLD it is widely acknowledged that there are a heterogeneous/diverse group of people with learning disabilities who have a complex range of difficulties (cf. Raising our Sights *How to* guide for Commissioners, 2013).

Children and adults with PMLD have more than one disability, the most significant of which is a profound intellectual disability. These individuals all have great difficulty communicating, often requiring those who know them well to interpret their responses and intent. They frequently have other, additional, disabling conditions which may include for example:

- physical disabilities – that limit them in undertaking everyday tasks and often restrict mobility; risk to body shape
- sensory impairments
- sensory processing difficulties
- complex health needs, (e.g. epilepsy, respiratory problems, dysphagia and eating and drinking problems)
- 'coping behaviours' (to their communication or other difficulties for example) which may present as challenging
- mental health difficulties

People with these characteristics are described as having profound and multiple learning disabilities (PMLD) or profound intellectual and multiple disabilities (PIMD). The compounded impact of a profound intellectual disability combined with other disabilities is multi-faceted and pervasive, meaning these individuals will require support with most or all aspects of their life. All, however, have the capacity to participate in everyday life in a way which is personalised to their needs and abilities, to benefit from good health care and education and are able in various ways to communicate their satisfaction or otherwise with their quality of life.

Emerging data demonstrates this low-incidence disability group of individuals with PMLD to be growing year on year. The causes of PMLD are many and varied. Causation may be ante-, peri- or post- natal and may include genetic disorders, brain damage as a result of infection and other acquired brain injuries. For many there is no known causation, but medical advances likely contribute to the growing numbers of children and adults with PMLD. Research by Emerson (2009), estimated the number of adults with profound intellectual and multiple disabilities in England to be 16,000. This number was anticipated to increase by on average 1.8% each year. From a survey undertaken in Scotland (The Keys to Life, 2013) it is estimated that the prevalence of PMLD in the general population is 0.05 per 1,000. This estimate would lead to a figure of 2,600 people with PMLD in Scotland. This is possibly an underestimate and a useful working figure would be 3,000.

The Department for Education figures demonstrate the significance of this rise, in England, based on their annual data collection. For example, 2009 statistics identified those with PMLD to be 9,400 aged between 5-16yrs. The 2017 report from the Department for Education, notes 10,981 pupils aged 5-16yrs are identified with PMLD as their primary need. These numbers will increase with better survival rates, not only in the neonatal period but into childhood and adulthood, due to advances in medical care.

The Same As You? (Scottish Government, 2000) raised awareness of people with learning disabilities and this resulted in many improvements in services for people with PMLD in Scotland. However, in England, the Raising Our Sights (Mansell, 2010) report recommendations has been less successful in effecting change for this group. This low incidence population are recognised to continue to experience significant inequalities in the services they receive and remain amongst the most isolated and marginalised in modern society, and by default so too are their families. They continue to be a group at high risk of experiencing inadequate and non-personalised services, despite this recognition ((Fergusson, 2016, Harflett et al, 2015). People with PMLD can and do lead meaningful lives but they require a high level of support with respect to all activities of daily living. Not only do people with PMLD require fully trained staff with specialised knowledge of their healthcare and

communication needs but communities need to be made fully inclusive through the provision of both intellectual and physical access. Despite improvements in service delivery in the last decade, people with PMLD continue to confront barriers to good quality health care, education, leisure activities and support services.

Aims of the Standards

The aims of the Standards are to support in ensuring people with profound and multiple learning disabilities, children and adults, have access to consistent high-quality support throughout their lives, when supported by any service provider. The ambition is that these Standards will be adopted nationally.

The standards outline key objectives and principles that should be evident across all education, health, and social care services. These should be adopted by commissioners and providers of services, ensuring families and other key stakeholders have awareness of these standards. Families and other representatives should be clear, from the outset, of what level and type of standards to expect for the person they represent and advocate for.

Widespread application of the Service Standards should result in:

- Consistently high standards of support, regardless of where the person lives and spends time.
- Enhanced quality of life, and life opportunities for the person and his/her family.
- Good physical and psychological wellbeing for the person, with access to specialist input as relevant to the person to maintain wellness.
- Improved health outcomes, with a focus on 24-hour postural care management, minimisation of hospital admissions and promoting longevity of life.
- Expressive and receptive communication being maximised with the person being supported.
- Enhanced and meaningful social and community participation, access and inclusion.
- Agencies and services working in partnership with the person and their family/advocates to ensure effective communication and working together in the person's best interest at all times.
- A workforce that is competent and confident to deliver high quality care and support to individuals in a personalised manner, within organisations that are committed to people with profound and multiple learning disabilities.

Failure to recognise and adopt these standards, will put at risk people with profound and multiple learning disabilities and their families/carers. If action is not taken to improve services then this will impact on the person's quality of life, their health and emotional wellbeing, leading to marginalisation and social exclusion, burdening for carers (emotionally, socially and financially) and increasing costs to health and care services overall.

Who are the Standards aimed at?

The Service Standards are designed to be used by educational, health and social care providers and commissioners of these services – to work together to ensure consistently good practice in all settings.

Education, Health and Social Care Providers; families and carers

The intended purpose is that providers will self-assess against the Standards to evidence a commitment to the highest possible service to the people they support. Through regular assessment, monitoring and planning for continuous improvement, providers will use the Standards to ensure people have increased participation and enhanced life experiences and outcomes.

Providers are advised to assess themselves on an annual basis with a focus on the Organisational and Individuals' Standards. The outcomes and subsequent action plans will be shared with relevant commissioners, families/advocates and regulators. The standards can be also used by families and carers and by people who are self-directing their individual service though direct payments or other funding, to set a benchmark of quality.

Commissioners

The Service Standards provide a framework that commissioners can use to clarify expectations with providers and outline to families what can be anticipated from the services being purchased. The Standards can be used to review services, ensuring the delivery of a quality service and identifying where standards need to be enhanced.

In addition, commissioners are able to use the Standards at a strategic level, when developing local plans and specifications for future service delivery.

Shared Responsibility

Providers and Commissioners must work collaboratively with each other, and other stakeholders to ensure support and service delivery is safe and of a high quality.

Quality assurance systems should ensure:

- The positive life experiences of children and adults with profound and multiple learning disabilities are central to all decision making
- Timely and regular monitoring and review of services and support planning to meet needs, and deliver measurable outcomes for people
- Shortfalls are addressed with effective action planning to ensure continuous improvement
- Concerns are addressed within an effective, honest and transparent process

The role of the Regulator (CQC, CSSIW, Ofsted)

It is anticipated that providers of services will be able to use the Service Standards to evidence effective service delivery. Likewise, the Regulator can use the Service Standards alongside their own standard measures to verify evidence of the specialist nature of services supporting people with profound and multiple learning disabilities.

How to use the standards?

These standards are a practical tool and an inter-agency means of ensuring high quality support to people with profound and multiple learning disabilities and their families. We encourage third sectors agencies (including for example, care providers, commissioners, educational establishments) as well as families and carers, to use them as appropriate to the individual and to their own support and needs. These standards can be used as a self-assessment to evidence areas of good practice and others that need improving.

This first set of standards aims to give guidance and support to organisations on how to provide high quality care to people with profound and multiple learning disabilities. Their emphasis is on all levels and ranks of an organisation's structure and how each can contribute to delivering such support. Organisations need to comply with the following standards in order to provide quality of care and life to the person with profound and multiple learning disabilities. A second set of standards, focuses on the individual and their specific needs. Organisations are called again to self-assess against these standards to identify actions to improve the quality of the support they provide.

The structure of each standard is as follows: each standard is numbered and with a generic title. The first section explains what each standard means and provides a brief description, whilst the second section contains bullet points with specific details about this topic.

The Standards are meant to be used as an internal auditing tool and we envisage the regulator, commissioners, families and other stakeholder will promote and embrace their use across the sector. We recommend such self-assessment to take place on an annual basis as a minimum, or as often as an organisation feels they need to revisit and re-evaluate their own practice. We anticipate organisations will respond to any shortfalls by implementing action plans to address any areas

of underperformance. We encourage the production of a portfolio which the organisation will keep up to date, and is equally useful for a regulatory inspection. Such portfolios, can provide examples of evidence that can be used against each standard be it documentation, observation, analytical procedure, evaluation or reflective accounts.

We are considering establishing a virtual Community of Practice for the PMLD standards, to enable all those involved in supporting people with profound and multiple learning disabilities (including professionals and families) to share practice in order to improve the support people receive. This initiative will provide networking opportunities, sharing and dissemination of knowledge, peer support and a mutual understanding of best practice. Ultimately this collaborative work will promote cross-organisational communication and raise the profile of this group of people by influencing policy and practice and by achieving social impact.

Core & Essential Service Standards for **Organisations**

Standard 1: Leadership

What does it mean?

- Show evidence of promoting a culture of strong values and accountability, risk taking, creativity and of using reflective practice productively and in line with national best guidance and evidence based practice.
- Recognise and respond to the holistic vulnerability of people with profound and multiple learning disabilities and ensure the quality of their physical and mental health status.
- Demonstrate inclusivity of people with profound and multiple learning disabilities in all their organisational practices and provisions.

Evidence that it's happening

1. Clear, written statement of policy and practice commitment to meeting the health, social and educational needs of people with profound and multiple learning disabilities is available and accessible to staff, people being supported and family members.
2. At least one member of the Executive Team/Board/Senior Management Team has specific responsibility for organisation-wide implementation of evidence based practice for people with profound and multiple disabilities. Leaders in the organisations have relevant training.
3. Supporting staff will receive ongoing CPD (continuing professional development) and be guided, trained and competency – assessed by all health professionals (physiotherapists, occupational therapists, GPs etc.) to ensure effective support

of complex healthcare and mobility needs to maintain wellbeing/quality of life. Examples of training may include: postural care, sensory support, enteral feeding (cf. Standard 2, point 12 on Standards for Individuals).

4. The organisation will have clear healthcare, and engagement/involvement related policies, procedures and protocols to ensure staff have clear guidance on how to fulfil their role.
5. The organisation will liaise with key health professionals including Physiotherapy, Occupational Therapy, Speech and Language Therapy etc, to ensure people supported have good access to assessment, input and equipment to meet health and mobility, communication and participation/engagement needs.
6. The organisation will evidence the involvement of people with profound and multiple learning disabilities in all areas of their lives, such as meeting their social and health needs, staff recruitment and training.

Standard 2: Quality

What does it mean?

- Ensure an effective quality assurance and improvement strategy using quality and auditing tools that create a learning environment for all staff.
- Show commitment to an honest/open culture of practice where staff are listened to, empowered and their knowledge is recognised.

Evidence that it's happening

1. The organisation has clear quality monitoring and auditing processes to continuously evaluate the quality and culture of service provision.
2. The organisation monitors and responds to complaints and compliments to assist with assurance and improvement.
3. There is visible and creative evidence of an enabled and fulfilled life for people being supported.
4. Feedback is gathered and acted upon from people being supported, families/advocates and other relevant stakeholders. Organisations give consideration to how to meaningfully gather the opinion of individuals who do not use words to communicate.
5. A range of data is collated, analysed and actively used to improve service delivery. This includes information about Safeguarding Alerts, Near Misses, injuries, risk assessments or accidents and incidents impacting on the wellbeing of people e.g. choking incidents, pressure sores, falls, frequent hospital admissions.
6. Positive data collection includes e.g. community inclusion, participation in social and leisure activities, access to voluntary or paid employment, reduction in medication/hospital admissions/epileptic seizure activity.

7. The use of Restrictive Practices (including the use of regular or PRN psychotropic medication, physical intervention and restraint) is closely monitored, in accordance with the Deprivation of Liberty Safeguards (DoLS). There is evidence of a commitment to reduce the use of Restrictive Practices.
8. Involvement (individuals and their relatives/advocates) is key in the organisation's priorities (business or improvement plan) and is implemented in all possible processes such as Best Interest Decision Making, supported decision making, recruitment, quality assurance, training, policy review for example. A Best Interest Decision is a legal process and there needs to be evidence of compliance with the MCA.

Standard 3: Staff development (skills and confidence)

What does it mean?

- Provide well-trained and supported staff, deployed in the right places at the right times
- Show evidence of values' based recruitment

Evidence that it's happening

1. All supporting staff are provided with an appropriately paced induction to ensure the new staff member is introduced to the person/people they will support at a pace the person/people are comfortable with. New staff are not engaged in complex health interventions until trained and deemed/assessed as suitably competent.
2. All support staff receive regular in-house training, refreshed at appropriate intervals. Such training includes Total Communication, Manual Handling of People, Postural Care, Intensive interaction or Sensory Engagement, Active Support, Safe Eating and Drinking skills, Supported Choice and Decision Making, involvement in services etc. There is evidence that the specific mandatory training provided is dictated by the needs of the people being supported and the risks to their wellbeing.
3. Staff receive training and guidance around risk and taking risks for participation/ engagement.
4. Staff receive supervision regularly, including safeguarding supervision.
5. All Managers and staff in a leadership role (including shift leaders, frontline managers) receive more extensive training related to meeting the needs of people with profound and multiple learning disabilities to ensure competent, safe practice and role models.

6. Organisations ensure that agency/bank staff are appropriately trained, receiving training relevant to the person/s they will be supporting, and will always work in conjunction with a member of staff who knows the person/s well.
7. Other people with disabilities (experts by experience) and relatives are involved in recruitment and training (e.g. values based recruitment) so they share their own experience and knowledge and act as an advocate for the person with profound and multiple learning disabilities.

Standard 4: Physical Environment

What does it mean?

- Ensure appropriate and responsive physical environments are delivered for each person to meet their individual needs.

Evidence that it's happening

1. The organisation ensures people live and spend time in environments which are:
   a. Within a local community, fostering relevant networks and links within that community.
   b. Appropriate and personalised in response to individual needs and preferences e.g. sufficiently spacious to ensure people can move freely, adapted to meet sensory needs, facilitate the use of assistive technology, structured and predictable to promote communication and enable some control.
   c. Equipped appropriately with hoisting, bathing /showering/changing and other mobility equipment people require.
   d. Suitable for the person's individual needs such as sensory needs and preferences, being functional and personalised at the same time.
2. People have easy access to all facilities where they live (e.g. kitchen, gardens, laundry facilities, and in non-residential setting such as education establishments). There is evidence that these facilities are well maintained at all times.
3. People have access to appropriate transport, which is available when the person needs it.

Standard 5: Communication

What does it mean?

- Ensure effective and consistent communication with each person, by supporters who develop warm and trusting relationships with the person/s they support.
- Ensure staff are trained in appropriate total communication approaches to maximise expressive and receptive communication.
- Appropriate communication aids, including assistive technology and concrete *routine and environmental cues*, are in place to promote communication and decision making in the persons best interest, acknowledging their perceived wishes and known preferences at all times.

Evidence that it's happening

1. Services evidence how they embed the Five Good Communication Standards (Royal College of Speech and Language Therapists, 2013).
2. The person has a comprehensive assessment of communication and they are supported to make their preferences known, take part in supported decision making in their daily life and about the services that they use.
3. There is a clear strategy to ensure that the person's preferred communication strategies and aids are continued across all settings the person spends time in, and when the person is transitioning from other services/family home.
4. Services ensure the environment and equipment is appropriate for the person's communication preferences, including the use of assistive technology.
5. Staff are trained in the methods of communication that best match the needs and abilities of the people with whom they communicate. Where it has not been possible to ascertain the views of people with profound and multiple learning disabilities, services demonstrate how it was attempted to do this and how the service design and delivery reflect the perceived wishes, feelings, preferences of people they support (Goodwin et al., 2015).
6. The leadership will role model and monitor the effectiveness of engagement and rapport, to ensure interactions are not purely functional, but warm and meaningful.
7. Services will ensure staff are aware of and respond appropriately to indicators that the person may be in pain, discomfort or distress.

Standard 6: Health and Wellbeing

What does it mean?

- Ensure effective support to promote the health and wellbeing of each person, including any specialist health care needs that increase the vulnerability of the person.
- The service has signed up to and demonstrates commitment to the Health Charter for Social Care Providers (VODG, 2016).

Evidence that it's happening

1. Staff receive training in supporting the emotional wellbeing and mental health of people.
2. Staff receive high quality training and competency assessment in all aspects of the physical and psychological needs of the people being supported. This includes postural care training, relevant medical/health training and mental health awareness training.
3. Staff receive Infection Prevention and Control Training, and there is evidence of effective infection prevention and control measures in place.
4. The organisation ensures staff have an understanding of the significance of common health conditions on the (high rates of) mortality of people with profound and multiple learning disabilities. Staff will demonstrate timely/early intervention to prevent escalation or in response to all health concerns and by routine monitoring of an individual's holistic health; they will ensure the people they support have Annual Health Checks and an accurate and up to date Health Action Plan.
5. The organisation ensures each person has an End of Life Plan in place, in consultation with the person, their family and other appropriate members of the circle of support.
6. The organisation demonstrates there are mechanisms in place to actively share knowledge with family/professionals/other settings to ensure continuity of care and support to maintain and promote wellbeing.
7. The service has good knowledge of local support and services available to support the person's health needs and maximise access to these as relevant e.g. access to community based sport and leisure activities. Such knowledge is shared with the person's family.
8. The organisation ensures the service has access to knowledge of current research and 'best practice' guidance relating specifically to people with profound and multiple learning disabilities, and associated health care needs.
9. Where possible, services contribute to research projects to advance knowledge and expertise.

Standard 7: Social, Community and Family Life

What does it mean?

- Support each person to maintain strong family and friend contacts, for the benefit of the person being supported, and to ensure effective partnership working with the people most important to the person being supported.
- Demonstrate strong leadership seeking to create new opportunities for people and their families to form wider social relationships.
- Show commitment to promoting good quality social lives for the people being supported, as well as active community participation and inclusion.
- Ensure each person has a Person-Centred plan promoting and supporting meaningful daily activity

Evidence that it's happening

1. Services will work closely with the person's family and friends to ensure effective communication, partnership working and close involvement in the person's life.
2. Services ensure people have full citizenship rights and acceptance/respect within their social circles and local communities.
3. The organisation ensures stability in staffing support to maintain continuity, to enable trusting relationships to develop.
4. The organisation ensures supporting staff are skilled and have a positive attitude to engaging and developing rapport with people being supported.
5. The organisation ensures effective social inclusion for people, to ensure people supported are able to be present and contribute to the communities they spend time in.
6. Inclusion in activity is participation at a meaningful level to the person involved, not simply tokenistic by simply being present, for example, through the use of Active Support.
7. Services support people to ensure they have access to transport that meets their needs and ensures ease of access outside their home.
8. The organisation has a clear policy related to Positive Risk Taking, to ensure people have carefully risk assessed and planned opportunities to enhance independence and gain new experiences – as individuals and with others.
9. Support staff are provided with training in how to facilitate activities in ways that make them meaningful for the people involved.
10. The service engages with people from outside the setting to support social involvement e.g. family, friends, other community groups.

11. The service demonstrates innovative practice in the development of social activities for each person.

12. Care and attention is shown to the social life within the setting. Conversations will be between supporting staff and people being supported.

13. People will be supported to engage in interactions with their peers, within their home and to develop friendships outside of where they live.

Core & Essential Service Standards for **Individuals**

Standard 1: Communication

What does it mean?

- Communication, in its entirety, with the individual is developed considering the individual and staff are equipped with appropriate training, knowledge and resources.
- Communication should be a collaborative activity, it has to be a two-way exchange; reciprocal and responsive.
- A means of communicating (that is acknowledged), a reason to communicate and an opportunity/available communication partner are crucial - all three aspects are needed for communication to be effective *(Coupe O'Kane and Goldbart, 1998)*

Evidence that it's happening

1. **Person**
   - **a.** Communication is determined by the person, intentional or otherwise. The individual's personal communication style receives universal respect at all times. Those seeking to communicate with the person do so using their unique communication style.

2. **Staff**
   - **a.** Staff form an active part of a process of enhancing joint communication skills: their own, as well as those of the individual. Staff have an understanding

of their role as a communication partner (facilitator) and they have an understanding of the fundamental principles of communication.

b. Continuity of communication is demonstrated, with information being shared consistently, paying particular attention to gaining insight from those who know the individual best (e.g. family and familiar support staff) and then as many perspectives as possible, utilising as many avenues for understanding (e.g. intensive interaction, sensory engagement such as hydro, massage, music, responsive environment etc.) and at transit points (e.g. going home at the weekends, moving between settings).

c. Information on functional communication will be documented within the service. This information will be accessible (in a range of formats - for example, digital passports), current and provide sufficient detail for the supporting team and others to engage well with the person.

d. The service supports the person in communicating their identity: e.g. how they dress, the lifestyle they wish to lead, their cultural identity etc.

e. Staff have access to tools which identify indicators that suggest the person may be in pain, discomfort, or distress (e.g. DisDAT). Such tools will be current and updated regularly and this information shared.

3. Method

a. A total communication approach is consistent and persistent, processing time responsive, predictable routines and repetition, and approached with creativity and imagination. They also consider the environment and contexts that promote communication e.g. social interactions, and pre-intentional or intentional signals. Opportunities are given to someone to communicate – not just functional or directional, but to comment on or about life. Communication is always at a pace the person can engage with. This may require patience and time; it is personally tailored and may change over time.

b. Supporting staff are skilled in delivering a total communication approach, e.g. sensory engagement, intensive interaction, routines and sensory cues, objects of reference. This can happen by offering a wide range of training such as non-verbal communication, reflection on own practice sessions.

c. Staff demonstrate an understanding of how repetition and routine can lead to predictability and anticipation, and greater participation. Using communication strategies will lead to better participation in all activities. Staff have time to get to know the person and their means of communication, so they can develop skills on creating communication opportunities. Staff recognise and understand various levels of communication.

4. Resources

a. The person has an up to date and portable Communication Passport/Profile, accessible at all times. This is a living item and ideally needs to include videos etc.; assessments are on-going and based on observations.

b. The person's communication enables them to access other services/activities/settings.

c. People have access to Speech and Language Therapy, audiology, ophthalmology for assessment and recommendations on communication strategies. Settings seek follow up and on-going support for implementing these recommendations.

d. People have access to a rich range of communication experiences e.g. support staff – person, person – public, peer – peer, group communication e.g. singing, story sharing, etc.

e. Individuals have access to a range of high and low technological tools appropriate to their communication needs e.g. AAC tools, objects of reference and environmental cues.

f. All individual means of expressing their preferences, choices and decisions will be assessed and shared to ensure that people are given maximum opportunities to express their views.

Standard 2: Health and Wellbeing

What does it mean?

- Each person's health and wellbeing are actively promoted and supported, to enjoy a full and long life. This will include a clear focus on postural care management and a recognition of the holistic vulnerability of people with profound and multiple learning disabilities.
- Each person has a thorough Annual Health Check with their GP and a Health Action Plan informed by health professionals involved with the person and made meaningful to the person by those who know them well.

Evidence that it's happening

1. Each person has a thorough Annual Health Check with their GP, to promote wellbeing and ensure all the person's health needs are being identified, met and monitored. Local health services and other professionals/specialists are known to the staff and are utilised to contribute to the Annual Health Check (e.g. 6 monthly dental check, annual Flu vaccinations, annual/biannual hearing and vision/eye health checks) and at other times, when needed.

2. Effective, comprehensive and current health assessments and Health Action Plans are in place for each person to promote physical and psychological wellbeing. Through routine monitoring, all concerns can be responded to in order to prevent chronic or common health conditions and personalised for each individual (e.g. constipation, dehydration, UTI) escalating. Summary Care Records (www.bit.ly/2zr70jj) with additional information are discussed with GP and

considered for all individuals to support effective sharing of key health information about the person with other NHS health professionals.

3. Staff have an awareness of what good mental health looks like for each individual and will develop strategies to ensure good mental wellbeing.
4. Each person with limited movement, and those who use a wheelchair, have a 24-hour postural care management plan in place with input from physiotherapy and occupational therapy at all stages. Plans include seating arrangements, night and daytime positioning systems, any medication prescribed to assist with postural care, the use of equipment e.g. wheelchair, standing frames, orthotics, pressure relieving equipment etc. Postural Care Management Plans are developed following postural care assessment by a trained therapist and where implemented by support staff they should be appropriately trained and competency assessed.
5. Staff have a good awareness of what is 'usual' for the person in terms of their health and wellbeing, and are able to identify and respond swiftly to indicators of changes in health status (physical or psychological/emotional and mental health). Staff are aware of how an individual communicates their health needs, including indicators of discomfort, pain or distress – and be responsive to these communications.
6. Supporting staff have a good awareness of the person's sensory needs sensory needs and/or their sensory processing needs, abilities and preferences. The supporting team are able to evidence how this knowledge is constantly updated.
7. Each person has a Hospital Passport, with staff skilled at liaising with the hospital/ LD Acute Liaison Nurse to ensure adjustments are made to suit the needs of the person and quality of health provision to the person. Effective communication and support will be in place throughout the admission period, and pre-discharge planning in place to ensure the person is ready for discharge and any change in need can be met.
8. The service ensures effective communication with all relevant professionals to share knowledge and information about a person's wellbeing.
9. Each person is given appropriate support to enable them to exercise and have control over their lives and decisions about their health and wellbeing.
10. Where appropriate (i.e. over 16) there will be evidence of a mental capacity assessment (MCA) and best interest decision making.
11. Each person is provided with respectful and dignified support to do as much as he/she can do for him/herself. This may take more time, but will be supportive of good mental health, countering learned helplessness.
12. DNACPR (DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION) plans are only in place as appropriately agreed via best interest decision making and in line with the Mental Capacity Act 2005 (www.bit.ly/2ztoPyi). End of life plans are also in place for individuals via best interest meetings and the MCA.

13. Nutrition, hydration and constipation information is known and personalised by staff for each individual. People with profound and multiple learning disabilities will be supported to express their choices for meals.
14. Each person has clear advice and guidance from a SLT or specialist healthcare professional to ensure their individual needs are met to keep them safe when eating/drinking. Staff will be appropriately trained and supported to adhere to these guidelines. This advice is reviewed and updated routinely and prompt referrals are made to changes in needs.

Standard 3: Meaningful/Quality Relationships

What does it mean?

- A sense of belonging is a vital element of the person's quality of life.
- The person is empowered and enabled to do things; not 'done to' the person.
- Approaches to meaningful engagement are honest and realistic
- The person is enabled to develop and maintain positive relationships (in their own home and beyond)

Evidence that it's happening

1. The significance of consistency of staffing and support on meaningful relationships is recognised. The service plans rotas to reflect this need, for example through key-working approaches or maintaining consistency of support to engage in daily activities or other events.
2. The service proactively supports quality time and contact with the person's family and friends, as the person wishes.
3. Staff are skilled at enabling people to engage in activities that foster participation and the formation and nurturing of relationships.
4. A personalised approach is evident, as not all social environments or opportunities will suit everyone being supported.
5. An individualised approach is evident for the range of social opportunities offered to a person, aimed at creating and fostering relationships that suit him/her.
6. The service demonstrates that they engage with a range of people/professionals in creating opportunities for the person to form meaningful relationships. Staff enable people to establish and maintain rapports with other people.
7. The service is aware of the interests of the person, and provide opportunities for the person to share their interests and to meet and connect with others who have similar interests.

8. Change (e.g. loss, bereavement, change) is managed by staff to ensure that changes are thoroughly and smoothly implemented. Loss and change are not one-off events and staff will support individuals with activities and opportunities that allow them to 'remember' people or events -for example by sharing photo albums personalised sensory stories or life boxes.
9. Staff understand the implementation and benefits of safe touch (functional use of touch vs. natural and emotional touch) and intensive interactions techniques.

Standard 4: Social and Community Life

What does it mean?

- Social and community life is about thriving and not just surviving.
- People are "visible" and actively involved in their communities and the activities they do; they are not passive recipients.

Evidence that it's happening

1. Each person is supported (with regard their likes and wishes), to participate and be included in their communities and to achieve citizenship in a meaningful manner.
2. Each person is supported to develop and maintain connections with people in their communities.
3. Choices are informed primarily by the person, with knowledge and support of those that know the person best.
4. The service demonstrates their detailed knowledge of the person's preferences, likes/dislikes and be able to evidence how these inform decision making about social activities.
5. Staff know how to source social opportunities that are accessible for the individual, by taking positive risks and facilitating social inclusion.
6. Each person has the opportunity to engage in spiritual practices appropriate to their needs and interests, (spirituality is not exclusively about religion). Opportunities for numinous experiences can address a person's spiritual needs.
7. Accessibility; staff are aware of accessible facilities for the person such as Changing Places toilet facilities; swimming pools that are accessible for people with profound and multiple learning disabilities etc. The service demonstrates active awareness of the accessibility of venues people make use of, and the transport arrangements to get there. Planning in advance is evident, particularly when planning to travel a long distance and/or over a long-time period.
8. Each person is supported to participate in social and leisure activities personalised around perceived and known interests and choices and that provide recreation and are fun.

Standard 5: Meaningful Time

What does it mean?

- Recognise the need for everyone to participate and be actively engaged in activities personally enjoyed and with people they like to spend time with.

Evidence that it's happening

1. There is evidence that people spend their time in ways that are meaningful and fulfilling to them. This includes time spent actively as well as passively, time spent socially and in solitude.
2. A person's opinions and known preferences feed into the choice and development of activities.
3. Each person is an active participant in the activities they engage in, their actions and responses determining what happens/contributing to proceedings.
4. The person is supported to have high aspirations and to achieve goals meaningful to them to promote and enable a fulfilling life.
5. Individuals are supported to experience new or different activities and events. Staff plan these and/or prepare the person where possible but are sensitive and responsive throughout, responding to any potential expressions of preference. Evidence of appropriate preparation and planning would demonstrate how this develops in a meaningful and enjoyable way.
6. Each Person will be supported to participate within every day activities and to develop the ability to engage with everyday tasks in a way that is meaningful to them.

Standard 6: Transitions

What does it mean?

- Change and transitions are an inevitable part of normal life. Some of these transitions are predictable and can be well-planned in advance (e.g. leaving school or moving away from the family home); other transitions may be unexpected however, they also require a sensitive, personalised and timely response.
- From children-to-adults' service transition, early planning (from the age of 14 or earlier) is vital to the coordination of this predicted, major transition.
- There is a need to identify responsible health professionals and an allocated coordinator to drive the transition plan forward.

- Good working arrangements between different education, health and care services and families.
- Other transitions, for example, moving from a college environment to a community based provision, or moving from one place of residence to another, for example, should be considered and careful planning, preparation and support for ALL situations of change is available wherever possible – not just big life changes.
- Staff consider how phased transitions or small steps of experience can empower and enable people with profound and multiple learning disabilities to more fully engage and enjoy new or challenging experiences.

Evidence that it's happening

1. Commissioners and health professionals listen to and learn from the person, their families and those who know them well.
2. Existing best practice is taken into account when planning the transition.
3. All health professionals involved in the care provision of the person will work collaboratively for the transition.
4. Consistent staff who knows the person's history are involved in the process.
5. A named professional is responsible for the planning and for seeing the process through to transition.
6. All parties involved ensure good communication and sharing of information so the provision of care is integrated and inclusive.
7. Funding arrangements are in place and organised from early stages on the transition process (where appropriate).
8. All parties involved are responsible for the success of the transition plan.
9. Continuity of support arrangements: the provider ensures that all support needs are met when the person transitions from one setting to another considering local variations e.g. the person transitioning from a college where they have good access to therapies, to their local community.
10. The needs of carers and relatives are also assessed as part of the process and any arrangements are carried out jointly with families where their views and opinions are considered.
11. Training and accurate information is provided to families to be prepared for the transition.

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Further reading

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Resources

Raising Our Sights: how-to guides and films to improve services for adults with profound intellectual and multiple disabilities

In 2010, Professor Jim Mansell published a report called *Raising Our Sights*, which looked at services and support for people with PMLD. In the report, Professor Mansell outlined what needed to change to improve the lives of people with PMLD. Mencap and the PMLD Network have produced a series of 11 how-to guides and 6 films to help local areas meet the needs of people with profound and multiple learning disabilities (PMLD). These how-to guides focus on his key recommendations and were funded by the Department of Health. The How-to guides cover the following topics:

- How-to guide 1: **advocacy**
- How-to guide and film 2: **clinical procedures**
- How-to guide 3: **communication**
- How-to guide 4: **health**
- How-to guide and film 5: **housing**
- How-to guide and film 6: **personalisation**
- How-to guide and film 7: **support for families**
- How-to guide 8: **training the workforce**
- How-to guide and film 9: **what people do in the day**
- How-to guide and film 10: **wheelchairs**
- How-to guide 11: **commissioning**

The guidelines are free to download from www.bit.ly/raising-our-sights-guides

mitre

Supporting people with profound and multiple learning disabilities

Core & Essential Service Standards

cmg

PMLD LINK

The Sensory Projects

choicesupport