

RAISING THE BAR THROUGH INCLUSIVE THEATRE

An evaluation of The Isle of Brimsker by Frozen Light
- a multisensory theatre performance for adults with
profound and multiple learning disabilities

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1. EXECUTIVE SUMMARY

Introduction

Frozen Light are a small performance arts company dedicated to providing high-quality theatre in mainstream arts and theatre venues, for people with profound and multiple learning disabilities (PMLD). The knowledge, expertise and drive of this company stems from the creative talents of its two Artistic Directors, Lucy Garland and Amber Onat Gregory and their combined first-hand experiences of working with children and adults with PMLD in a variety of contexts. From the insights they had each gained into the lives and limited opportunities of this population, Frozen Light's Artistic Directors developed a shared commitment to taking a proactive approach to improve the outcomes for this overlooked group.

People with profound and multiple learning disabilities are a low incidence population who are amongst the most marginalised and isolated in our modern world. They experience inequalities and inequities in the life chances and services available to them. From a continued lack of personalised opportunities and services, they experience reduced overall outcomes, poorer health status (even preventable, earlier death) and a less favourable quality of life. Despite evidence of this ongoing situation, this group continues to be overlooked, ignored and even invisible to those in positions to effect change in their lives (for example, Mansell, 2010; Harflett et al., 2015; Fergusson, 2016; Doukas et al., 2017, LeDeR, 2018 and 2019).

Those who care for them and enable them to access the world, their families and paid supporters, are also isolated by association; they too miss out - on opportunities for vital specialist training or receiving essential professional support, both of which are crucial to being able to provide the most appropriate and empowering support for the individuals with PMLD to whom they provide care.

Rationale for this Evaluation

In recent years Frozen Light has produced four unique, immersive and multisensory theatre performances for individuals with PMLD. *The Isle of Brimsker*, their most recent show, was designed specifically as a performance dedicated to adults with PMLD as they are a more ostracised element of this forgotten population.

The audience feedback routinely collected from Frozen Light's shows has always been overwhelmingly positive although somewhat general in form. The Artistic Directors were keen for more candid and focused comment in order to actively learn from feedback to further improve their work and the whole theatre-performance experience for their target audiences. This evaluation was commissioned with that task in mind.

An independent reviewer with insider-experience was invited to undertake this evaluation. The review process drew from a range of methodological approaches to gather together contextual information, theatre-visit observations and the views of a wide range of stakeholders. Once collated, this information was analysed for common themes and then mapped against a quality assurance framework designed specifically for this focus population – 'Supporting people with profound and multiple learning disabilities; Core and Essential Service Standards' (Doukas et al., 2017). For the purposes of brevity, this shall hereafter be informally referred to in this report as 'the PMLD Standards'.

The PMLD Standards comprise two sets of inter-related standards. The first set focuses on outcomes for the individual with PMLD from a holistic, quality of life view. Topics in the Standards for Individuals relate to their communication, health and wellbeing, relationships, social inclusion, meaningful activity and transitions. The second set, Standards for Organisations, relates to the key actions of an organisation as a provider of services in the broadest of senses. These standards focus on leadership, quality, workforce development, the environment, communication, health and wellbeing, and family and community life. They describe the essential practices of those providing 'services' (of any nature) needed to operationalise the Standards for the Individual – each set of standards are dependent on the other to be accomplished.

Frozen Light are an organisation with strong values. They aim to be agents of change in shifting society's outdated view of those with disabilities as being 'less able' in every aspect of their lives (the medical model). Their work is underpinned with a clear commitment to overcoming the attitudes and barriers imposed by society on people in this group, by instead, raising expectations and improving their quality of life outcomes (the social model). This stance offered a valuable starting point for this evaluation. The review consciously explores and bolsters the investigative journey with the spotlight focused on purpose – 'the Why? question' as Simon Sinek would suggest (e.g. TED Talks, 2009). In order to set a context in which to examine the more predictable questions about How? and What? Frozen Light do, this review considers which beliefs, purposes and causes drive 'Why Frozen Light do what they do' so that the resulting outcomes have more meaning.

Impact and influences: *The Isle of Brimsker* theatre experience

Audience Feedback

Frozen Light supplied an overview of their own post-show audience feedback from the 2019 performances. Whilst this data had limitations, it offered some valuable insights about the 'reach' and actions of theatre venues to;

- **appropriately programme and market *The Isle of Brimsker***
- **accurately identify and understand the needs of this target audience: adults with PMLD**
- **develop their own local audience base of adults with PMLD**

build both an appropriate programme and a 'reputation' for accessible theatre that meaningfully includes adults with PMLD

This feedback data contributed post-show ratings of *The Isle of Brimsker* performances and the valuable free text views of audience members, both aspects contributing to the wider evidence gathered by the review process.

Adults with profound and multiple learning disabilities (PMLD), the target audience

Individuals with PMLD, the focus of this review, were clearly the main beneficiaries of this dedicated theatre experience. First-hand observations witnessed by the reviewer across ten shows, offered a valuable yardstick of consistency and quality from the Frozen Light performances, which took place across a number of theatre venues for a variety of diverse audiences and companions. Regardless of settings and their variables, every show attended was of equally high quality in every respect - the offer to every audience was comparable.

Feedback from audience members and other stakeholders was unanimously positive. Without exception their views demonstrated clear benefits to adults with PMLD, backed by constructive comments about levels of engagement and active participation, of individuals using their skills, taking the lead and expressing their views, for example. Companions and invited 'expert reviewers' enthused about the new responses they witnessed and unexpected levels of the concentration and perseverance often never seen in these adults before. They also spoke of the

mutual enjoyment from sharing the experience of this spectacular multisensory theatre extravaganza with their companions with PMLD.

Views from the complete range of stakeholders provided clear and overwhelming evidence to endorse achievement of each of the six Standards for Individuals within the PMLD Standards. In many cases the evidence revealed exemplary practice by the Frozen Light team and their work, in supporting and empowering people with PMLD. The report comments in detail on the creative and informed design of *The Isle of Brimsker*. The specialist approaches and techniques used by Frozen Light to overcome the many barriers experienced by this audience to include and engage them in this theatre experience are documented against the PMLD Standards for both Individuals and Organisations.

Wider issues

In order to develop a sound context for this evaluation, a range of literature and other documentation was scrutinised and discussed, with the most relevant issues highlighted in the debate as part of the review process. These broadly addressed personhood and human rights, exploring values and attitudes, access, opportunities and expectations. It acknowledged social inclusion, co-dependency and the sense of community, and of course the role of the arts as both a context and a vehicle to respond to these aspects of the lived experience for adults with PMLD. Analysis of stakeholder views within that context identified similarly common strands, in the main echoing those topics recognised in the literature and these strands are therefore examined across this evaluation report.

When exploring the experiences of *The Isle of Brimsker* theatre visits for adults with PMLD, many external factors were identified as having influence and impact on the overall outcomes. These wider issues were acknowledged to be relevant indicators of both the frequent opportunities and barriers people with PMLD commonly experienced in their lives (and so too their families and paid carers by association). These issues were considered within the context of the PMLD Standards for Organisations reflecting on a number of key perspectives as appropriate, namely the roles of:

- **Frozen Light**
- **theatre venues and their personnel**
- **those supporting adults with PMLD**

The benchmarks within the Standards for Organisations indicate how an organisation might operationalise the outcomes as detailed in the Standards for Individuals. This review analysis located evidence that demonstrated which benchmarks were achieved, and to what degree, whilst also highlighting where there were shortcomings or gaps in provision by services. Responsive actions are suggested to many of these limitations and barriers experienced by adults with PMLD.

Findings

Without question, this evaluation found a wealth of high-quality evidence from the work of Frozen Light to support every aspect of the PMLD Standards – for Individuals (adults with PMLD - their target audience) and as an Organisation and provider of services themselves. In particular, the review ascertained that the positive benefits to their audiences with PMLD were consistently perceived and supported by every stakeholder group involved in this review. These verified audience outcomes can be directly attributed to the creative and well-informed theatre design by Frozen Light and their execution of a high-quality piece of theatre. Furthermore, their exemplary, truly person-centred practice is vital to augmenting those expert attributes first mentioned – and worthy of note as cutting edge. However, the benefits and influences of their work, particularly their innovative models of working with the wider arts and disability communities reaches far beyond the audience of adults with PMLD themselves.

Embracing diversity, influencing positive change

Frozen Light push the boundaries. Despite being a small-scale organisation, they lead by example. They demonstrate huge potential influence and the necessary drive to act as catalysts for much-needed change - for audiences with disabilities and differences, to their enablers and supporters, to theatre venues and, to the wider arts and local communities. In their empowering offerings to adults with PMLD, *The Isle of Brimsker* provided security and safe places from which they carefully and creatively supported individuals to take risks and venture into unknown territory. Their theatre companions, recognised as key to enabling successful engagement and participation, were also challenged – in many instances the person they were supporting responded in completely new and unexpected ways, forcing the companion to raise their expectations to a new baseline.

Attitudes and prejudices were challenged in the case of theatre venues (and their personnel), but these challenges need to pervade the arts more widely. The work of Frozen Light incites the arts world to reconsider the slow-moving agenda of widening participation and restrictive concepts of inclusion, to more authentically

adjust their notions of accessible and relaxed performances from both social and environmental perspectives. It is time to contemplate a new way of thinking about theatre and arts communities to more fully reflect the complete local population in future audience membership and opportunities.

This Frozen Light performance is a master class in one hour. Their quality acts of preparation and attention to detail with every stakeholder in mind, provide the sound and vital foundation that leads to its success. Engagement, participation and enjoyment of the show are simply the tip of the iceberg. We need to raise our sights, not only on what is possible, but what is vital for people with PMLD to lead fulfilling lives and contribute to society with full citizenship.

The Isle of Brimsker lighthouse becomes somewhat symbolic – the work of Frozen Light shines a light on change, lighting a new way. Individuals with profound and multiple learning disabilities themselves are leading that new way. What we can learn from this group of individuals is profound and transforming, it demands we think and act differently – to have a better future for all, we must raise our sights. *The Isle of Brimsker* offers a new narrative by raising the bar of inclusive theatre.

2. Introduction

Frozen Light was grown out of a desire to make theatre for audiences that don't usually access theatre in mainstream arts venues

frozenlighttheatre.com

Introduction to this evaluation report

The invitation to evaluate the work of this small but innovative theatre company presented an extremely rare opportunity. This occasion offered the remarkable prospect of forging uncharted inroads, not only into the perceived concepts of inclusive theatre and relaxed performances, but more significantly into the lived experiences of people with profound and multiple learning disabilities (PMLD), one of society's most forgotten groups.

The strong relationship between our overall wellbeing and that of being connected with others, of being actively engaged in meaningful activity that gives purpose to our lives, is gaining greater recognition. We 'know' that the compounded effects of loneliness and isolation together with the pervading influence of stress and anxiety affects our wellbeing, leads to poor health status and even early death. These are situations we can remedy without 'prescribed' medical intervention or medication, rather with small but significant changes in the way our communities live and work.

Together, this review process and the evaluation report create a situation through which to begin to genuinely acknowledge and understand the incredibly unique lives of this invisible group of people. The focus specifically is on adults with profound and multiple learning disabilities (PMLD), with the intention that as a result of our learning from this review, we may change the current status quo - to improve (hopefully radically) their outcomes and their wellbeing, and ultimately, their quality of life.

Frozen Light Theatre Company

Frozen Light is a relatively new company, formed in 2012 when the expertise, talents and strong vision of Tell Me A Tale and Seeing Beyond combined forces.

The embryo that is now Frozen Light began in 2006, when Lucy Garland and Amber Onat Gregory studied together at university for their Masters in Applied Performance degrees. Following this period, each went their separate ways yet taking complementary routes, to create multisensory storytelling shows for children and young people with PMLD. Lucy's company Seeing Beyond worked across East Anglia, whilst Amber's London-based company Tell Me A Tale also performed in Turkey, Dubai and Australia. During this time, they also gained valuable experience and insights from supporting individuals with disabilities; Lucy worked in social care as a support worker for adults with learning disabilities, and Amber worked as a teaching assistant in schools.

Their shared experiences of touring theatre performances to school settings for children and young people with PMLD highlighted that often audience members would range in age from three to nineteen. They became acutely aware these shows did not always offer the most appropriate experience to their older audience members in terms of their age or relevant narratives. An Arts Council England grant in 2012 enabled collaboration between the two theatre companies, to create a theatre production specifically for 13 to 25-year olds with PMLD. This partnership, as Frozen Light, was driven by a shared vision and passion. Their goal was to enable the opportunity for this low incidence population to access high quality, accessible and meaningful multisensory theatre, appropriately performed in local mainstream arts or theatre venues.

Frozen Light have created and toured four performances since forming— TUNNELS, The Forest and HOME. Moving forward, Frozen Light became increasingly aware that there was an even greater need for opportunities for adults with PMLD. The fourth and most recent show, *The Isle of Brimsker*, was devised specifically for this older audience group and is the focus of this review.

As a charity Frozen Light aim to:

- **create and tour high-quality theatre for people with PMLD in the UK**
- **enable theatre venues and professionals to increase access for audiences with PMLD, and learn about the importance of programming art for a different demographic**
- **support people with PMLD, in what is often their first theatrical experience and encourage their companions to help support them in accessing the arts in future**



The audience: adults with profound and multiple learning disabilities

To clarify and explain who the audience were - individuals with profound and multiple learning disabilities - this review adopted the working definition and broader description detailed within 'Supporting people with profound and multiple learning disabilities (PMLD); Core and Essential Service Standards' (Doukas et al., 2017), for brevity referred to in this report as the PMLD Standards.

An extract from these standards is shared here for reference.

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 (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 may also 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 & 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 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.. (pages 13-14)

It is important to stress that people with PMLD are people first - they are much more than a label or a set of descriptions. Each individual is unique and valued in their own right, for their inimitable personality, their talents and their qualities. The rationale for sharing this 'profile' is to offer a greater understanding of their distinct needs and the barriers they face, in order to respond with the best access and support.

Some question this terminology has taken on a derogatory connotation and stigma, as it has with other terms describing groups with features in common. However, in order to lobby and effect change, we need to be clear about who we mean. Imray (2019) suggests that any avoidance of identification (and labelling) will not prevent stigmatisation, but rather it may be detrimental in itself, preventing people getting access to appropriate services to ensure their holistic and unique needs are met.

One useful position to adopt is to consider the term as merely the start of a conversation about the positive distinctiveness of each person. The term 'profound' can equally apply to the degree of responsibility and challenge we face, to ensure each person has the right access to a meaningful life. Or, perhaps more valuably, to the profound learning and benefits we gain from spending time with people who live so mindfully and 'in the moment' (e.g. Pamis 2017).

Individuals with this complex profile of disability form a low incidence group. They are a long-overlooked minority population, too often invisible within what we consider to be our ever more inclusive modern world. Once leaving education, where these individuals have been valued within a school or college community, they can quickly disappear. They enter into the world of adult services very often with no peers, no familiar base to go to, nor a 'community' to belong to.

Appropriate opportunities for adults with PMLD are too often scarce and limited in scope and creativity. It is not uncommon to see adults with PMLD and their carers wandering through shopping malls or on solitary walks through the park. Individuals may participate in meaningful activities but frequently they do so without a peer group, undertaking activities alone with only the support of a paid carer. The chance to develop friendships is rare, with relationships more often mere acquaintances – they continue to be invisible. The direct impact of such limiting influences is seen in the low-quality outcomes and poor health and wellbeing status of this population. *The Isle of Brimsker* is a high-quality piece of drama, using relevant narratives of transition, loss, friendship and positive change. Set on a desolate island in the midst of turbulent seas, it tells the story of a lighthouse keeper who is about to lose her home and life purpose when the lighthouse is decommissioned. On her last day, a stranger is washed up on Brimsker; their paths and lives cross. Sharing their challenging situations, they help each other. Together they are stronger and take valiant steps into their new futures.

The Isle of Brimsker

The Isle of Brimsker is a high-quality piece of drama, using relevant narratives of transition, loss, friendship and positive change. Set on a desolate island in the midst of turbulent seas, it tells the story of a lighthouse keeper who is about to lose her home and life purpose when the lighthouse is decommissioned. On her last day, a stranger is washed up on Brimsker; their paths and lives cross. Sharing their challenging situations, they help each other. Together they are stronger and take valiant steps into their new futures.

Frozen Light created this very accessible immersive and multisensory piece of theatre especially for audiences of adults with PMLD. Many members of this audience had never been to a theatre before or had experience of live or multisensory performances; the experiences of their companions were often the same. As a consequence, this audience were unknown to theatre venues and unfamiliar to their personnel. Frozen Light developed pre-show information for their audiences – a simple visual story for adults with PMLD and some clear information about expectations and the supporting role of companions. Theatre venues were offered face to face, written information and hands-on support for the whole workforce at every stage [for example <http://frozenlighttheatre.com/resources/isle-brimsker-resources>]. This UK tour aimed to tackle this lack of awareness, the poor visible profile of this group and the low expectations and public attitudes towards people with high support needs.

More detailed insights into this performance, its approaches and techniques are described throughout this report.

The show was toured at locations across the UK, in 53 arts or theatre venues and with 222 performances. Each show offered seats to six adults with PMLD (the target audience), plus their companions. Other audience members could include family members of the adults with PMLD, theatre staff, colleagues from the arts field and other interested or invited parties. This evaluation invited a number of people to participate in the review process.

3. A context for this evaluation: the wider picture

Personhood and rights to social inclusion

People with profound and multiple learning disabilities (PMLD) continue to be one of the most overlooked, marginalised and isolated groups in our modern society and so too their families and paid carers, by association.

They continue to be a low incidence group despite a year on year growth in the size of this population (mostly as a result of medical advances); however, they remain a minority everywhere for other reasons. It is not solely the size of this group that relegates them to the side-lines but much more about how they are perceived or included by communities and the value placed on them within our wider society as a whole (e.g. PMLD Network, 2008; Mansell, 2010; Harflett et al, 2015; Fergusson, 2016, Doukas et al., 2017).

The UK, as a developed country, has national and international laws and policies to protect marginalised citizens, the assumption being that governments (and others) will make every effort to promote these rights and requirements in order to give such ostracised groups the same entitlements and opportunities as their fellow citizens. At the start of this millennium, the UN Convention on the Rights of Persons with Disabilities (UN CRPD), as a human rights treaty, set out clear guidance to protect the rights of every disabled person. Its guiding principles included respect for dignity, autonomy and diversity, non-discrimination, full and effective participation and inclusion in society, and equality of opportunity – including issues of accessibility (UN, 2006).

Belonging or othering

Marginalised groups by definition are powerless, viewed to be unimportant by communities and wider society. By default, they face social exclusion and disadvantage, being denied full access to the rights, resources and opportunities that are available to others. Recent research around the life experiences of adults with PMLD highlighted exactly this disparity, revealing them as isolated from opportunities and excluded from communities (Harflett et al., 2015 and Fergusson, 2016). Mansell, in his 2010 report, found adults with PMLD were recipients of prejudice, discrimination and low expectations from many quarters, but particularly those in positions of power – decision-makers and gate-keepers who controlled access to funding and services. We now have clear evidence that such inequities result in significantly poorer health and wellbeing status, lower quality of life outcomes and preventable, earlier death (e.g. Heslop et al., 2013; LeDeR, 2019).

Nind and Strnadova (2019) examine the perspective of 'belonging' within the context of those with profound intellectual disabilities; of being included (and by association the sense of belonging or membership) or being excluded (and deemed outside or 'other'). When considering the societal position of people with PMLD they suggest the term, and even the concept, of inclusion may not be most helpful. They offer instead the idea of community as a more valuable and helpful alternative from a stance of ethics, values and rights.

The importance of social inclusion cannot be overstated. Powell (2019) proposes,

'... the problem of the 21st Century is othering. Looking around the world, we see inter-group conflict as central to almost every human problem: territorial disputes, war and conflict, climate change, migration, economic inequality. Group identities and differences informs almost all of them'.

www.haasinstitute.berkeley.edu/video-building-belonging-time-othering-john-powell

Other recent bodies of work expand on social and community exclusion of this group, suggesting people with PMLD are ostracised further from within the disability community. This population feel alienated; left out even from the wider learning disabilities world itself, thereby experiencing further isolation and additional disadvantage – and from the very sources where they should expect most support (Doukas et al., 2017; Bovell and Palmer, 2019). It remains the case that those with the greatest intellectual impairment have little or no voice. They have experienced little, if any, benefit from the disability movement 'nothing about us, without us' (Ferguson, 1994, cited by Feder Kittay, 2019).

Low expectations

This philosophical discourse however cannot continue without acknowledging the context in which these individuals live. People with PMLD cannot escape from a world of co-dependency. However enabling the environment, they will always be dependent on others for most (or even all) aspects of their lives.

Maslow's Hierarchy of Needs is familiar to most. Using a pyramid of needs, he originally identified five incremental tiers describing the human motivation for life. This hierarchy set out at its base, what he considered 'deficiency needs' - the most basic of human requirements (food and water, health, shelter and safety). Once achieved, progress upwards was then possible, to what he viewed as more mature, social and psychological needs of community, social interaction and self-worth. Following achievement of these, the individual was able to continue on to reach their potential and a fulfilling life. We can make some sense of his incremental hierarchy as human beings across the geographical and cultural divides of the world.



Based on Maslow's *Hierarchy of Needs*

Should we consider this hierarchy for people with PMLD, we recognise some key differences in their experience. Firstly, they are reliant on others to enable them to access and achieve at every tier. Others are essential to meet even their most basic needs, but to make progress towards much greater aspirations – as you or I would consider as simple expectations of an 'ordinary life' – the role of others is even more vital in facilitating and empowering their progress.

A second major difference for people with PMLD when considering their outcomes against such a framework, is their experience of prejudice and discrimination. Evidence shows there is a pervading attitude of low expectations and inequities from many providing the finances and services essential to their lives. Their unequal access to opportunities and high-quality services across health, education, social care, arts, leisure and community providers leads to poorer outcomes (e.g. Mansell, 2010; Harflett et al., 2015; Griffiths, 2015; LeDeR, 2019).

When addressing such differences of life experience compared to the general population, people with PMLD sit in an unequal power balance. They are, by default, beholden to the values and attitudes of these 'others'; it is 'others' who decide whether or not they are deemed 'worthy' enough for equity and equality in their lives (Chapple, 2019). The very language itself is a political tool of comparison, used to determine status and access to services along a spectrum of quality. WHO describe inequities of health as 'avoidable inequalities' in health between groups of people' within and between countries. This can be interpreted as 'the more favoured people are, socially and economically, the better their health' (Marmot, cited in Low, 2017).

The Health Equalities Framework (HEF) (UK Learning Disability Consultant Nurse Network, 2013) was developed in the UK as a proactive response to the staggering and continuing statistics of the Learning Disability Mortality Review Programme (LeDeR, 2019), that people with learning disability die more than twenty years before their non-disabled peers; the median age of death for people with PMLD is 41 years. They die, not because of their disabling conditions, but because they do not get access to appropriate, high quality services and care. The HEF, identifies the social determinants of poor health and wellbeing in people with learning disabilities and, in particular, recognises the prominence of 'social disconnectedness'.

The 'principled approach' adopted by the Care Act (Legislation.gov.uk, 2014) in England exists to promote and improve an individual's wellbeing as an essential aspect of the legal 'duty of care'. The detail of the act specifically identifies social (and economic) wellbeing, relationships, participation (in work, education, training and recreation) and an individual's contribution to society as being integral [Sect 1:2].

Similarly, quality of life (QoL) measures recognise that the indicators are influenced by more than good health (or the absence of poor health). Fergusson's (2016) research explored perceived benefits to quality of life as an outcome for adults with PMLD living in Lambeth, as a consequence of participating in the Carousel Project activities programme. A central part of this Carousel Project programme was to make adults with PMLD more visible and create greater inclusion in the local community:

'As people with PMLD gained greater access to their local world, so they raised awareness of their presence, as part of Lambeth's community and offering their valuable social contribution' (p31)

The review emphasised that contributing factors to improved quality of life were those impacting on positive emotional, mental health and general wellbeing, with social inclusion being a very strong influence.

Attitudes, values and opportunities

Health 2020, a current focus of the World Health Organisation (WHO), aims to improve health and wellbeing and reduce inequalities internationally. In examining the cultural context of wellbeing, WHO views good health as an asset contributing to a nation's economic and social stability, whilst also reinforcing a growing belief that any judgement of a nation's status goes beyond the common concept measured by its gross domestic product. In particular, it favours a broader view including measures of wellbeing [WHO 2.2.2: 88-90]. WHO plan to develop a means to identify factors of influence, giving 'social connections' as one key example.

Raising expectations, changing attitudes

Mansell's (2010) report, 'Raising our sights', recommended commissioners, services and providers 'raise *their* sights' beyond the low expectations they commonly held for people with PMLD. Meeting only the most basic of peoples' needs for care and safety was simply not good enough.

Too often, funding of any services or provision for people with PMLD is limited by being considered too expensive, applying assumptions of poor 'value for money' or 'cost effectiveness'. This population, by the very nature of their profile of needs, will always require high levels of support, which will always be expensive. However, when auditing any type of provision through these financial lenses for this group, measurements need to be based on a different set of criteria. The PMLD Network responded to Mansell's recommendations on this by developing guidance for commissioners and others (PMLD Network, 2013):

Services for people with PMLD need a high level support staff, and so will always be high-cost. To establish the value for money of services for people with PMLD, the focus needs to be on:

- *higher quality of life*
- *lower costs on families (including nonmonetary costs)*
- *lower needs in other areas (e.g. health)*
- *or lower needs in the future, rather than lower costs of the package of care.*

The value for money of many services for people with PMLD can be measured in terms of the prevention of issues that would negatively affect quality of life or would require more expensive interventions. Health services in particular can be measured in this way, as can services to support carers and social care services that facilitate participation and wellbeing for the person with PMLD.

(Raising our Sights How to guide 11: Commissioning p33)

Raised expectations and greater understanding of this group by those holding the power and the purse strings would lead to better outcomes, to ensure they have access to appropriate and meaningful activities outside their homes, including opportunities for work (or experience of work-related activity), to continue learning and for leisure – a life that you or I would consider to be a given. The more recent quality assurance benchmarks of 'Supporting people with profound and multiple learning disabilities: Core and Essential Service Standards' (Doukas et al., 2017) offer more appropriate criteria for judgement on the quality of services. The PMLD Standards give clear information about the quality outcomes expected for individuals, as well as details of the practice that is indicative of the essential high-quality care and support required to operationalise and enact these outcomes.

People with PMLD have value as any other person, yet their families and carers continue to experience low expectations, negative attitudes, inequalities in services and a lack of opportunities, that tell a very different story. They feel that these individuals with PMLD are not valued and their contributions to society remain unacknowledged.

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. (PMLD Network, 2008)

Vorhaus (2019) enhances this debate on valuing people with profound disabilities. He provokes us to reflect on what it means to be seen as human, exploring in his discourse the intrinsic characteristics we all share by belonging to the human species; dignity is one such example. He gives the example shared by the parent of Harriet, who once ripped off her clothes and nappy pad in a public space. Her female carers formed a protective circle around her, to respect her dignity, despite her own lack of awareness of this. He challenges us to consider how acceptable it would be to allow Harriet to be seen naked in a public space. Are people with PMLD afforded the same human dignity as any other person, whether or not they have the capacity to understand it? He suggests we would be appalled and would view this as a gross violation of the full and equal human dignity Harriet is entitled to, irrespective of her disability – 'and not one jot less than anyone else' (p14).

As a reviewer attending ten performances of *The Isle of Brimsker* at a variety of venues, frequent situations arose revealing the value (perceived to be positive and negative) placed by 'others' on audiences of people with profound and multiple learning disabilities, even towards meeting a basic human need:

One particularly stark example was in a northern city at a very large theatre, renowned for being inclusive. A family carer asked the theatre usher (possibly a volunteer?) for directions to the disabled toilet for her large, adult son who was in a very sizeable powered wheelchair. She was directed to the disabled toilet-cum baby-change room – a very small space with a tiny fold down

baby changing table – too small for their son’s needs. She asked if they had an alternative. I suggested ‘like a ‘Changing Places’ toilet’ – explaining that this gentleman needed to get out of his wheelchair - ideally using a hoist and with access to an adult-sized changing bed for his personal care.

Q *The theatre usher looked visibly aghast, replying, ‘What do you think this is – A&E?’*

Attempting to soften this offensive suggestion I added ‘but we all need to use the toilet don’t we? This man wants to feel comfortable so he can then go off and enjoy the show’.

Q *The usher continued, sounding indignant, ‘and who do you think would pay for those – “special toilets” then?’.* [her emphasis]

The man’s mother suggested the cost should rightly come from the same funding pot that paid ‘for everyone else’s toilets’.

Rather than risk injury to her son (or herself, trying to lift him onto the dirty toilet floor to be changed), this parent had to accept her son’s personal care needs could not be attended to until they returned home -that would be some hours later.

Not many theatre venues had fully accessible Changing Places (www.changing-places.org) facilities. However, other observations saw requests met by venues who made accommodations by offering an alternative space – often simply a clean room or office with privacy, for personal care needs to be met.

This example reveals the real-life experiences for people with disabilities (also experienced by their families and carers), of being seen as ‘other’ or different from those without disabilities. It conveys insights and exposes the values and attitudes of others. Explicit attitudes of discrimination need to be directly addressed (at this theatre venue, for example), but so too do the implicit attitudes and issues of rights and legal obligations around accessibility at many venues – the latter may be the result of being uninformed or, choosing not to know?

The role of the Arts: the benefits of access and enjoyment

More than a decade ago, the PMLD Network (2008) appealed for the complex and distinct needs of people with PMLD to be met, and to be met in ‘imaginative ways’. Just as for you or I, we need to acknowledge that ‘participation in cultural life is an integral part of the human experience’ (Mencap, n.d.).

Of particular interest here are the intentions of the Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) treaty relating to rights of people with disabilities to:

- **enjoy access to cultural materials in accessible formats**
- **enjoy access to TV, film, theatre and other cultural activities, in accessible formats**

Central to these entitlements to access the Arts, in all its forms, is the clear focus on enjoyment. Enjoyment can take the broadest definition, describing the process or state of finding pleasure or gratification in something – or possibly simply enjoying exercising your rights. Adults and children alike value ‘having fun’. Enjoyment and amusement, suggest increased interest and delight or fun in whatever you are engaged in. Neuroscience and MRI scans demonstrate that enjoyable experiences create many benefits. Physiologically, these experiences stimulate the release of chemicals in our body to create that ‘feel good’ sense. The Arts offers entertainment in many forms, but ultimately it leads to feelings of pleasure and mutual enjoyment shared with like-minded people, known and unknown.

Neurologically, enjoyable experiences stimulate the brain’s neurons to connect and create new neural pathways of learning. A familiar, but unpublished, quote by Dr Karyn Purvis suggests, ‘... it takes approximately 400 repetitions to create a new synapse – unless it is done with play, in which case, it takes between 10 and 20 repetitions’. People with PMLD mostly experience and understand the world through their senses and physical actions. Ongoing sensory stimulation is an essential requirement to maintain the brain’s functioning. Sensory deprivation is known to disrupt or prevent cognitive development, impacting on our abilities and understanding – the cliché, ‘use it or lose it’ applies here. Interacting with others and encountering sensory stimulation and sensations that are enjoyable – such as those created by multisensory theatre, will certainly aid and enhance every important opportunity for continued, lifelong learning.

Learning and making sense of the world is impaired when access to sensory stimulation is restricted. However, it becomes easier to renew and strengthen neural pathways when we have learned before and when using approaches that are enjoyable. Access to the Arts and especially multisensory theatre experiences offer a rich and stimulating opportunity for people with PMLD. The prospect of exciting active engagement in novel encounters and sensory experiences will result in impact and influence beyond simple enjoyment.

The Arts: the benefits of social inclusion and wellbeing

An All-Party Parliament Group (APPG) on Arts, Health and Wellbeing was set up in 2014 with the aim of increasing an ‘awareness of the benefit that the arts can bring to health and wellbeing, and to stimulate progress towards making these benefits a reality across the country’ (House of Commons Library, 2017). Following their inquiry of existing practice and engagement of the arts in health and social care (APPG AHW, 2017) they reported that the arts can:

- **help keep us well, aid our recovery and support longer lives lived better**
- **help meet major challenges facing health and social care: ageing, long-term conditions, loneliness and mental health**
- **help save money in the health service and social care**

According to this 2017 report however, the UK had made little more ‘than a small modicum of the potential contribution of the arts to health and wellbeing’, lagging well behind Australia, Cuba and the Nordic nations.

This report urged leaders within the arts and public sector services, along with academics and service users, to support and promote good practice, to develop a strong evidence base and disseminate research that could inform both policy and delivery at national and local levels. They recommended that Arts Council England should view health and wellbeing as a priority for its 2020-2030 Strategy and support arts and cultural organisations to ensure health and wellbeing outcomes were also integral to their work. In addition, they urged philanthropic funders to support these worthwhile endeavours.

Another pertinent recommendation for this context was the recommendation to raise awareness across public and academic sectors, to the benefits and contributions of the applied arts to health and wellbeing outcomes – thus, educating clinicians, health and care professionals and those studying in all aspects of arts and education. This action, accompanied by research into the area of participatory arts, health and wellbeing, could valuably contribute towards the necessary evidence base that may lead to nationwide signposting and NICE guidance on the use of the arts with this focus.

Low (2017) argues against the interchangeable use of the terms ‘health’ and ‘wellbeing’ within the context of the arts, preferring instead the notion of social health and wellbeing. She defines wellbeing as a social construct, with inter-relationships between individuals and communities. However, she cautions against the political focus, using notions of alternative supports to wellbeing as evidence that the wellbeing needs of our society are being met, despite austerity cuts to public services – namely citing the 2010 pre-election speech by David Cameron, before taking office as Prime Minister, on the power of the ‘Big Society’ to improve our society’s sense of wellbeing. Instead she views the concept of wellbeing as being akin to health, in a holistic and ‘all-encompassing sense’ that includes many influences on its status.

Exploring further the meaning of wellbeing, Low (2017) cites the definition used by Ings et al. (2012) in their evaluation of Arts Council England’s Be Creative Be Well programme. They advocate wellbeing as being much more than good health and happiness, but rather about the way people live and experience their lives – if they have a sense of purpose and opportunities to achieve, ‘a sense of belonging and being part of the social fabric, connected to other

people and supportive of local networks’. This programme, aimed at residents of impoverished London Boroughs, noted improved wellbeing by those accessing and participating in the artistic and cultural activities of the project. Low alerts us to another potential risk should we take up an instrumentalist approach to ‘using’ the arts in order to improve wellbeing. She highlights the danger of viewing the arts as a means to achieving a health goal, rather than exploring the arts activity in its own right, to ascertain its beneficial qualities. The latter consideration is of greater value to this population of adults with PMLD, and to this evaluation report.

Enabling access to inclusive theatre

The engagement levels of people with learning disabilities are known to be lower than those of the general public, with even greater risks for individuals with PMLD. A constructive, solution-focused view of what constitutes meaningful activity and opportunity is necessary to enable access and engagement to be effective. Adapting the environment and utilising responsive approaches are required to support and enable people with PMLD to be successful in participation. The value of activities experienced through the senses has previously been emphasised, both as a focus for engagement, but also as a stimulus to elicit engagement and as a prompt to facilitate participation. However, the added importance of enabling relationships and high-quality social interaction are key to the most benevolent outcomes.

Embedding ‘person-centred’, ‘active support’ can significantly increase the quality of outcomes for people with PMLD. Person-centred thinking and working should be self-evident, with its focus entirely on the individual, and every plan and every action being sensitive, responsive and personalised. Whilst principles of active support (e.g. Ashman et al, 2010) build on this further, noting core beliefs for supporting engagement well;

- **every moment has potential**
- **little and often**
- **graded assistance to ensure success**
- **maximising choice and control.**

Without the right opportunities, even with the right support, in the most conducive and responsive environments, individuals with PMLD will simply rebel or withdraw their attention. Sometimes responses viewed as ‘opting out’ (and sleeping) are actually simply a means to regulate their sensory overload. Others may default to the security and predictability of self-stimulation – a place of familiarity and under their own control. However, Pagliano cautions that the individual who ‘withdraws to their internal world of non-productive engagement ... ceases to be an active citizen of the world’ (2001, 2012).

To ensure such unreasonable demands are sensitively acknowledged and responded to, we must actively seek to build on our understanding of the unique needs, preferences and interests of individuals. Equally, we must be committed to recognising and promoting the voice and communicative attempts of people with PMLD, using specialist and appropriate approaches such as, for example, Intensive Interaction (e.g. Nind & Hewett, 2005), the Hanging Out Program (Forster, 2008) and supported decision-making (e.g. Goldbart, 2017; Ryan, 2017). Stone (2005) asserts, 'the ability to communicate, to be listened to and understood [is]...central to our experience of humans ... if our communications is not valued and understood, we become isolated, frustrated and disenfranchised.'

Narratives and multisensory theatre

Stories are important, they can confirm who we are. It has been recognised for some time that such narratives enable us to combine people, places and events in a way that helps us make sense of the world and learn from them (e.g. Bruner) and that they can be used for various purposes.

Some cultures remain totally oral, using spoken narratives and active storytelling as the only means of sharing their traditions and heritage at both a personal and collective level. People are interested and remember stories, more so where they relate in some way to our own lived experiences or, take us into new, imagined realms. Stories like this can transform us at the deepest levels, they can contribute positively to our emotional development and our resilience to cope with adversity and challenge - potentially leading to improved mental health and wellbeing (BoingBoing, n.d. <https://www.boingboing.org.uk/interactive-resilience-framework/>). This evaluation process draws on a range of narratives as a methodological approach to gather 'evidence', each of the stories helping to create a richer, more holistic picture of the experiences of people with PMLD engaging in performances of *The Isle of Brimsker*.

In this review process, one invited expert reviewer commented how:

'a typically developing child has multiple opportunities through childhood to meet themselves in stories and to experience drama. A glancing look at these things might presume them to be frivolities of little consequence. But a longer look recognises them as key to the development of an understanding of self, instrumental in understanding the world, both the world outside ourselves and the world of emotions within. Involvement in the arts is good for children's mental wellbeing and their development as citizens.'

The narratives within *The Isle of Brimsker* explore the awe, wonder and sheer power of nature and the elements, the intensity of human relationships and the mix of raw emotions these bring, all set within a multisensory extravaganza- a theatrical narrative in its

own right. Whether or not the audiences of people with PMLD could understand or even relate to some of these narratives at a conceptual level was not the focus, yet many audience members were observed appearing surprised and clearly emotionally moved to witness such theatre. Rather the aim was that the audience were immersed in the drama and direction of travel of this multisensory portrayal. These were opportunities for individuals to live beyond the often life-limiting restrictions of their disabled bodies, with the offer of some kind of shared meaning and purpose, a common identity that brought them together with others experiencing this same story and purpose – a sense of community perhaps.

A sense of community, dependency and an ethic of care.

The Centre of Welfare Reform, an international community of individuals who work together to bring about positive social change, is a 'citizen thinktank' campaigning for a more just world in which *'Everyone is equal - everyone matters'*. Simon Duffy, Director of the Centre challenges us to consider our greatest wishes and aspirations for our loved ones – Money? Power? Fame? Or, 'a life of citizenship: love, community and the freedom to be ourselves' (Duffy, 2017). Duffy publishes extensively on his thinking around improving the lives and social belonging of people with learning disabilities, notably the seven essential elements he deemed 'The Keys to Citizenship' (Duffy, 2009). His constructs of belonging and community, as part of full citizenship, include the role and contribution of its members. Duffy asserts 'if we understand the true nature of citizenship, we find it is open to everyone', (Duffy, 2017). Being visible, having a presence and participating in cultural activities in the local community are an acceptable expectation for every citizen.

Opportunities for such inclusion and involvement are currently too scarce (or non-existent) for adults with PMLD - this reality is unjust and is not acceptable. Currently there are possibly only three theatre companies creating appropriate multisensory theatre for individuals with PMLD across the entire UK (Griffiths, 2015). Two companies (Oily Cart and Bamboozle) make theatre for children and young people, in the main taking their performances into specialist school/college settings. Frozen Light have a different agenda, targeting their work to adults with PMLD and locating their performances in mainstream theatres and arts venues in people's local communities. The reality for audiences with PMLD is that such a performance will only come around every couple of years, if they are lucky – and funding permitting.

Returning to the subject of dependency, philosopher Feder Kittay maintains that we should recognise that dependency is actually fundamental to our existence as social beings, but it is most often viewed as a moral failing within modern society. Reflecting on

her life with her daughter Sesha (who has profound disabilities), she reasons this experience 'has made me see that we cannot understand the demands of social organization if we cannot take the fact of dependency as one of the circumstances of justice' (2019).

Feder Kittay advocates we must adopt a moral ethic of care for the disabled, particularly those with significant disabilities who will require life-long care (such as individuals with PMLD). Within this context she provokes us to contemplate issues, of personhood, dignity, rights and justice (also discussed elsewhere in this report). Her rationale for publishing such personal insights on her life with her daughter Sesha is driven because 'philosophy is so uninformed when it comes to issues of disability in general and cognitive disability in particular'; for example, she cites work describing the intellectual capacity of these individuals to that of a dog. She contends, 'And they get away with it. Too few people challenge them.'

Instead Feder Kittay's work addresses such misconceptions and social attitudes head-on. She queries the most basic philosophical questions about the very nature of 'a life with meaning' and 'what makes for a good life' when viewed through the lens of disability. She applauds the abilities of those with the most significant disabilities, to 'be present' in their life, to really notice and possibly appreciate the subtlest of nuances and sensations as they mindfully live 'in the moment'. Feder Kittay offers a strong moral construct, founded on the needs and abilities we each have to give and receive, to share care and love. She holds up the unique talents and capabilities of people with the severest cognitive impairments as the rich contributions they are to the world; she draws our attention to their capacity to *really appreciate* music, human interaction and joy-filled experiences for what they truly are. These are simply talents and gifts they can offer to those differently-abled members of their communities.

Communities need to employ collaboration to function, balancing and combining the strengths and qualities of their individual members to work most effectively. We might think communities are all about giving and helping others, and yet for people to be able to give help, other people are required to receive that help, to perform that role. People with PMLD will always need the assistance of others, thus creating employment opportunities for others and fulfilling this essential need within a community. Duffy challenges us to further consider the unique attributes and qualities that people with PMLD can valuably contribute to thriving communities (2017). Individuals with PMLD may engender compassion in us, they empower us - to think and act creatively (for example, in how best to provide access and appropriate care) and, as Feder Kittay reminds us, those with profound disabilities are superb role models for us to live our lives more mindfully. Duffy quotes from Jean Vanier's acceptance speech for the 2015 Templeton Prize:

'There is a revolution going on. We are beginning to realise that every human being is important. We are beginning to see that every human being is beautiful. At the heart of this revolution

are not the powerful, the wealthy or intelligent. It is the people with disabilities who are showing us what is important – love, community and the freedom to be ourselves'

However, we cannot expect this revolution to effect change without our concerted action. Elly Chapple puts out a clarion call to arms (2019). As the mother of a young woman with very complex needs, she admits to learning so much from that parental journey when sadly the education system failed her daughter Ella. However, her greatest learning came directly from Ella herself, causing her to view the world from a different side. She now demands we all change the story, we 'flip the narrative' to really see and value the person for who they are, first and foremost. She insists, 'Everybody needs a seat at the table and we need to drop the ridiculous assumptions ... it does not matter which package you arrived in ... we are all different, but we're the same because we're all human beings.'

Chapple challenges the invisibility of people like Ella, when in actual fact these individuals offer us vital solutions:

'Why are Ellas not seen everywhere, everyday in our homes, communities and our societies – all of the time? Why are they hidden? ... and locked away? ... and marginalised? ... and othered? And pushed out, still? Who decides? – we decide who deserves and who doesn't ... but who decided WE can do this?'

'Everybody needs more connection, compassion, creativity and diverse ways of thinking - they [people with PMLD] offer us insights into these ... their contribution to the whole.'

'Diversity is the key to our survival!'

(TEDxNorwichED Chapple, 2019)

Contributing to the furtherment of the arts

The engagement and participation of people with PMLD in authentically inclusive theatre pushes the boundaries of the arts world and leads the way to increasingly creative outcomes, that may never otherwise be explored. In a more equal world, decision-makers would be made to justify why they don't take action to create more accessible theatre, rather than it being a fight to convince others (funders and venues) that the needs of this group are as important as the rest of the population.

What a generous contribution ~ those with profound and multiple learning *disabilities are the true catalysts for change.*

4. The Evaluation

This independent evaluation was commissioned and initiated in January 2019, mid-way through *The Isle of Brimsker* tour. A number of in-house data collection methods were already established by this time, which focused on selected elements of the show to help identify its audience, its reach and its impact.

Focus

As with most theatre companies Frozen Light's ultimate aim was to provide a high-quality performance and theatre experience - a show that was enjoyable and entertaining for their audience and, located in local mainstream theatre venues.

Whilst some aspects of any performance evaluation are predictable from the onset (particularly those relating to funder requirements, such as number of venues, audience take up and demographics), the anticipated outcomes for this work carried an additional agenda, to explore potential for disability-related difference. There were incongruent expectations from funders when compared to general theatre audiences, where simple measures of satisfaction or enjoyment were deemed acceptable. The inference for members of this target audience, adults with profound and multiple learning disabilities (PMLD) however, was that attendance at a single, one-hour theatrical experience might have a greater influence and possibly even life-changing impact as an outcome. Consequently, a review with greater depth and breadth of examination was demanded.

As there were no agreed requirements from funders, time was needed to identify and prioritise the review focus and to consider the most appropriate methodology. A combination of visits to shows, review of initial feedback and dialogue with Frozen Light's Directors helped shape a focus that was of most value; it needed to reflect on *The Isle of Brimsker* show and its UK tour, and, to help shape future work to be of most effect. Two key issues were identified: the first and priority issue was addressing the benefits for people with PMLD; the second to acknowledge the relevant, wider issues that have a part to play in the experience of this group.

When considering Frozen Light's tour of the show *The Isle of Brimsker* to theatre venues across the UK, this evaluation seeks to respond to the question:

What are the potential benefits and influences of this multisensory theatre experience for young adults and adults with profound and multiple learning disabilities (PMLD) and to the wider community?

The role of reviewer and validity of the findings

An independent reviewer was selected for their professional and personal knowledge of profound and multiple learning disabilities (PMLD). A combined background as a university academic, consultant and researcher with a specialism in PMLD and an 'expert-by-experience' as a family carer of an adult with PMLD demonstrated experience and a sound understanding of this population. The reviewer was familiar with the work of Frozen Light with previous first-hand experience of their shows from an audience perspective. Additional credentials included being an editor of the journal PMLD LINK and co-author of the Core and Essential Service Standards; Supporting people with profound and multiple learning disabilities (PMLD) (Doukas et al., 2017).

Acknowledging potential for bias was important to the validity of the evaluation outcomes. Having a reviewer external to, and independent from, the Frozen Light Team was an important factor to ensure a neutral picture of the findings. However, with an inherent position as an insider-researcher/reviewer the possibility of influence was recognised. The duality of the role comprised objective critique as a researcher but, by contrast, subjective views and insights as someone with lived-experience of the barriers to inclusion and the contrast with aspirations of what truly meaningful opportunities and accessible amenities and services should look like.

One unexpected development to this role was that of the reviewer relationship with the Frozen Light Team which could be perceived as that of 'critical friend'. The ongoing dialogue, despite this being very informal, is an influence in itself that should be acknowledged.

Gathering information

The key purpose of this review was to seek evidence of impact and influence arising from individuals with PMLD attending Frozen Light's performance of *The Isle of Brimsker*. However, it also responded to a number of wider implications and issues arising from this theatre experience. It was thought valuable to explore these broader topics to gain a greater understanding in order to further develop and improve the arts opportunities and experience for this group in any future work by Frozen Light.

Approaches to the review process

The broad nature of the evaluation focus demanded a mixed methods approach. A wide range of approaches to gather views and information, when used together, can generate rich insights and valuable evidence. The ease and challenges of undertaking some of these approaches can themselves reveal information which is of little value but can, by contrast, highlight priorities and considerations that may otherwise be overlooked.

The following approaches provided data for consideration:

- **Document scrutiny (funding bids, publicity and website)**
- **Invited post-show feedback from the audience (companions)**
- **Reviewer visits to 10 shows, 5 venues**
- **Informal conversations 'in-situ' pre/post shows (companions, people with PMLD, theatre staff, guests, others)**
- **Personal stories and narratives gathered through the process of the evaluation**
- **Spontaneous feedback – social media and published reviews**
- **Invited Expert Reviewers (a range of experienced stakeholders: family members, PMLD/learning disability specialists, inclusive Arts specialists and students in this field)**
- **General observations**
- **Focused observations of performances (structure, approaches, sensory props, dramatic flow, etc), of individuals with PMLD (and by default their enablers) and of the whole 'theatre experience' (welcome, access, reasonable adjustments, staff attitudes, programming)**





- Semi-structured interviews with Frozen Light Team members
- On-going, focused dialogue with the whole Frozen Light Team at points during the latter half of the tour
- Review of relevant research and literature, comparable reports, legislation and policy to provide relevant contextual information
- Reviewer narratives were used to create contexts in which to discuss relevant aspects of the findings

Analysis

A number of approaches were used to analyse and consider the information collected from two broad perspectives. The first and central focus was to consider the people with PMLD and the impact and potential benefits of their Frozen Light experience. The latter focus was to explore the wider issues and influences highlighted from the review as a whole.

PMLD Standards

A published set of quality standards 'Supporting people with profound and multiple learning disabilities: Core and Essential Service Standards' (Doukas et al, 2017), informally referred to in this report as the 'PMLD Standards', were adopted as a framework for this analysis. This tool identifies specific quality indicators as benchmarks appropriate for any audit of provision for this population, regardless of their age, geographical location, the setting or type of service. It comprises two sets of standards, the first focusing on the individual with PMLD from a holistic, quality of life view and the second, clarifying expectations of those providing services (of any nature), as essentials to operationalise the standards for the individual.

Individuals	Organisation
1 Communication	1 Leadership
2 Health & Wellbeing	2 Quality
3 Meaningful/Quality Relationships	3 Staff Development (skills & confidence)
4 Social & Community Life	4 Physical Environment
5 Meaningful Time	5 Communication
6 Transitions & Change	6 Health & Wellbeing
	7 Social, Community & Family Life

An overview of the two sets of quality standards

The initial phase of analysis was repeated scrutiny of the post-show opinions shared by people viewing *The Isle of Brimsker* performance and their personal reflections of the experiences of the audience members with PMLD. These responses were colour-coded to recognise common themes and then mapped broadly to the PMLD Standards, specifically the six Standards for Individuals and the seven Standards for Organisations. This process was repeated for the responses from each of the stakeholder groups.

A second level examination helped identify relevant narratives that might provide context or evidence that would aid greater understanding of the relevance of the review evidence.

5. Findings and Discussion

The views of stakeholders

For the purposes of this evaluation, the following stakeholder groups were identified as participants, as visitors or involved in *The Isle of Brimsker* performances. Their diverse roles covered:

- Young adults and adults with PMLD (primary target audience)
- Companions i.e. paid supporters/carers, family members and friends (secondary target audience)
- Theatre staff (including for example programmers, front of house, box office, volunteer ushers, café and activities staff)
- Arts peers and funder representatives
- Expert reviewers (with general learning disability (LD) or PMLD experience) – these invited individuals covered a variety of background experience which included;
 - Family members
 - LD Advocacy lead
 - Sensory Impairment Advisor (vision, hearing and dual sensory loss)
 - Sensory Processing/Multisensory Activity provider
 - Sensory Engagement Consultant
 - LD Nurse
 - Health and Wellbeing lead
 - LD Social Care Provider
 - Theatre Programmer – Inclusive / Relaxed performances
 - Social care support workers
 - LD SALT
 - Special school teacher
 - LD Specialist Musician / Composer / Music Teacher
 - PMLD LINK Trustees
 - Drama student
- Frozen Light Team –actors/musician/performers and technician
- Frozen Light Artistic Directors

Approaches to gathering views

Formal and informal approaches were employed to gather the widest range of perspectives on *The Isle of Brimsker* performance itself, the whole 'theatre experience' for this target audience, the nature of Frozen Light's work and issues and insights from the UK-wide tour of 222 shows in 53 venues. Approaches to differing stakeholder groups varied according to the focus of their 'roles' and the available opportunities for participation. These included invited and spontaneous written comments via post-show feedback forms, social media and email communications, informal conversations pre and post-show (participants informed of my role in the evaluation), email discussions and written feedback from invited expert reviewers and a number of semi-structured Skype interviews.

The responses of people with PMLD to their theatre experience

Collecting the authentic voice of the target audience, (i.e. from people with PMLD themselves), as well as gaining their informed consent, was by nature of their severe communication difficulties an interesting challenge. In light of these, this evaluation actively pursued the proxy views of others as advocates, to offer observations and reflections on their perceived responses. In this context, those knowing the person with PMLD best were those accompanying them at the performance – in the main, paid supporters and PAs, sometimes family members or volunteers. Whilst acknowledging their companion's views were subjective interpretations of someone else's experience, it was felt these familiar carers shared the closest to genuine insights.

Several observations were made by the reviewer during performances of *The Isle of Brimsker*, to capture the range and types of responses in the moment from people with PMLD, acknowledging the contexts and approaches within the performance experience that had elicited these. These responses are reported later, alongside reflections on the show itself.

5a Post-show audience feedback

Frozen Light shared much of the information they had gathered from audience feedback across their UK tour. For the purposes of this review process, an overview of their analysed data on 2019 performances only was presented.

From the outset of this tour post-show information and feedback was collected by the theatre company for their own use, with information and responses entered onto their database. The initial printed format (used for the first six months of the tour) asked for responses to quite a number of variables, but this was seen to be too time-consuming. The format was later revised by the Frozen Light Team; the deliberately shortened version of the feedback request (postcard sized) made it more user-friendly. The reporting of findings presented in this report draws on the views submitted on this revised format during 2019, the remaining six months of the tour only.

Theatre staff at each venue distributed feedback forms to the audience (companions) as they left the theatre auditorium. Audience members were invited to share some basic information about the person they were supporting -their age, where they were from (organisation), if this was a first visit to a theatre, and if a first visit to a Frozen Light performance. Following this audience members were encouraged to give a rating score (1-10) on *The Isle of Brimsker* performance and its relevance to their companion with PMLD. These performance ratings are discussed later in this section. Opportunities for free text responses and mailing list sign ups were offered. These qualitative, free text comments are considered throughout later sections of the findings and used as evidence against the PMLD Standards criteria.

Initial findings

The quantity of data and resultant response rates from completed audience feedback forms were, at first view, disappointing. However, adjusted estimates for the total of respondents was broadly around a 33% response, which in research terms is not unexpected and, considered average for customer satisfaction-type surveys. However, there are some contributing factors that are worthy of consideration.

Accurate audience numbers are not clear from the collective post-show data. There are no definitive numbers for ticket sales or audience attendance across the tour of 222 shows. The figures presented here were created by Frozen Light's administrator and are based solely on the database for 2019 audiences rather than the overall UK tour. Each show had audience capacity for six people with PMLD, plus their companion(s) amounting to an overall maximum capacity of 1320 people with PMLD. Not every show reached full capacity – either from unsold tickets (particularly at new venues where their audience base was not yet developed) or no-shows on the day for a number of sold tickets. By contrast however a very small number of shows did have more than 6 people with PMLD in attendance.

A number of factors preventing uptake in completing audience feedback forms were observed frequently on reviewer visits. Common issues included insufficient staffing (not always 1:1 staff support), transport-related time constraints and the frequent group response to the optional feedback form. Most of the audience members attending *The Isle of Brimsker* were reliant either on using adapted transport (many of the people with PMLD were wheelchair users) or for transport to deliver/collect them from the theatre (usually school or centre minibuses or pre-booked taxis). Those attending in groups frequently rushed away immediately post-show, to return to their bases e.g. for strict medication times, set lunchbreaks or to meet end of the day transport home. Groups attending together (e.g. school or resource centre) would very often have shared support for the people with PMLD – not every person would have a dedicated companion. This meant support staff were being stretched to supervise their group whilst also responding to the personal needs of the disabled individuals (e.g. reassurance, assistance to the toilet or medical needs). People from groups would frequently complete one form on behalf of their group, thus skewing the data and response rates. Some individuals with PMLD, despite having enjoyed the show, could become eager to leave the unfamiliar theatre surroundings as soon as the multisensory experience was over, thus preventing the support worker from completing the feedback.

The total number of completed forms submitted from 2019 audiences was 407. Not every form had responses to each item, and fewer had free text comments to the general request for further comment.

Feedback form items

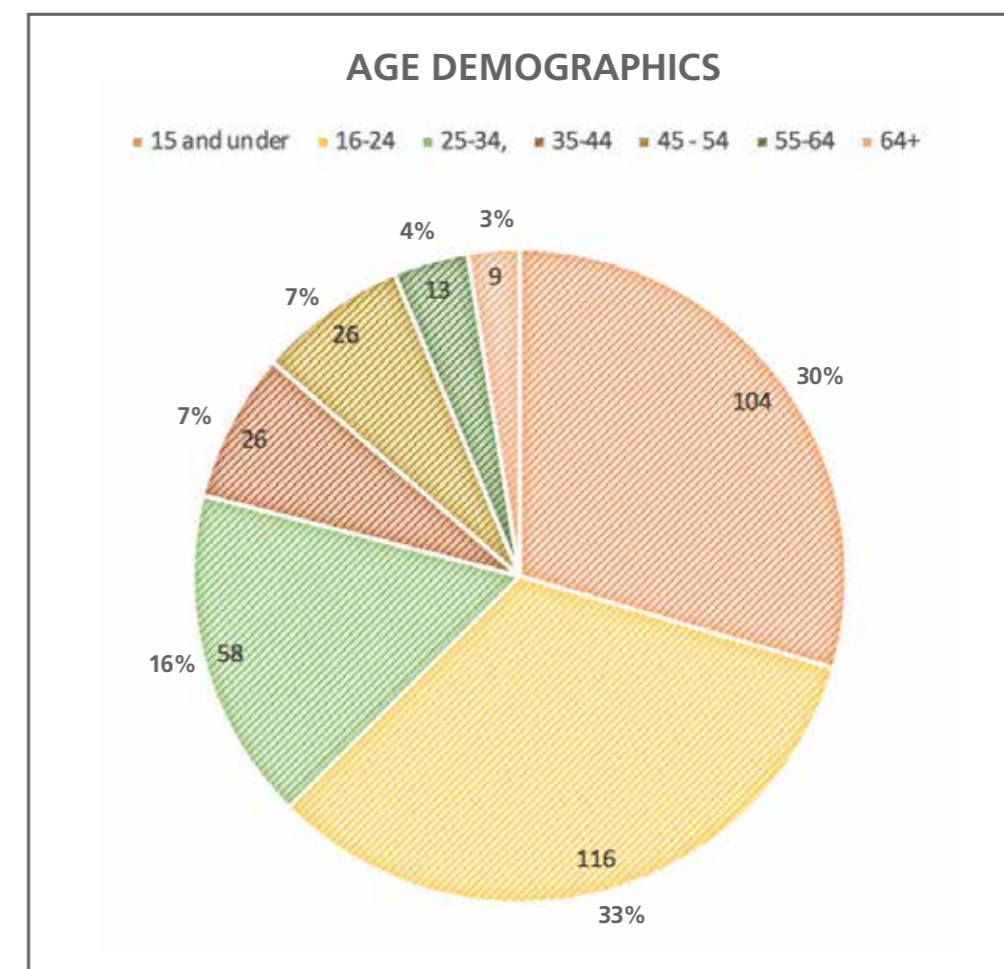
The following tables and graphs were supplied by the Frozen Light Team as standalone information. The full context or variables was not always clear.

1. Age

Companions were asked the age of the person with PMLD they had accompanied to the theatre (free text).

Age	Number
15 and under	104
16-24	116
25-34	58
35-44	26
45 - 54	26
55-64	13
64+	9
Total responses	352

Age Demographics
- Not all respondents completed this question.
Table and graph shown represents only submitted information.



The available data from Frozen Light showed that individuals attending the show were aged between 3 years and 75 years. *The Isle of Brimsker* is clearly promoted by Frozen Light as being designed specifically for young adults and adults with PMLD. Interestingly the largest proportion of the attendees (220/352) were within the age range eligible for provision of state education services (0-25years).

More detailed examination found 51 children were pre-teens, aged 3-12 years. It is unclear if these were individuals with PMLD (respondents noted hospice, care home and foster family on their forms), people accompanying the person with PMLD or invited, non-disabled guests.

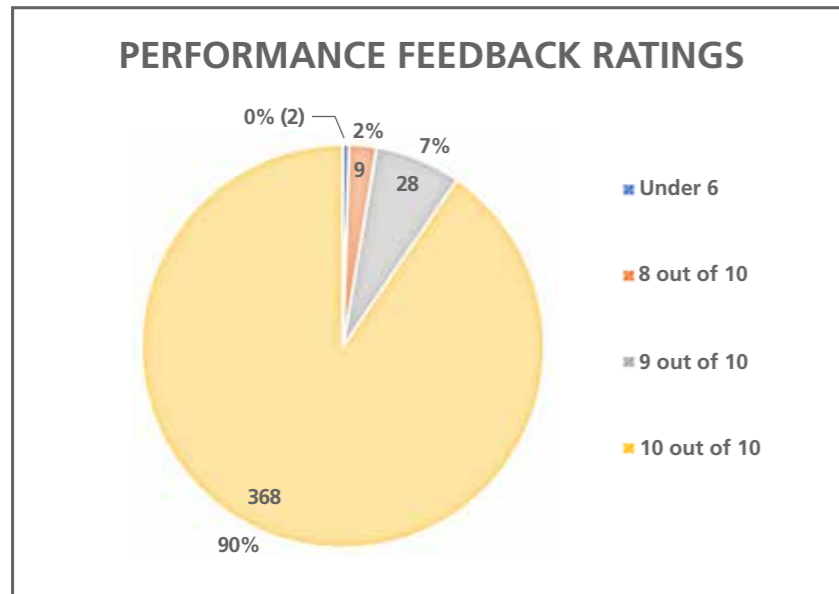
Not everyone completing the feedback entered information against this age question. From reviewer observations in-situ, it was common to hear staff asking each other the age of the individuals with PMLD – particularly for those beyond school or college age range. Some responses were marked as broad estimates (e.g. 25ish, 30-50, 30's, 40's 50's). Some responses gave multiple ages as a response to reflect the membership of their group (e.g. 19,29 + 18; 11,12 +18; 48 + 34; 6 +8)

2. Organisation

Few respondents completed information relating to the setting from where they had come. Informal conversations before the show highlighted attendance from special schools, colleges, specialist provider bases, day centres, supported living and residential care homes as well as family homes (especially weekend shows)

3. Rating the show

Respondents were asked to select a rating score to express the success of the show for people with PMLD. The rating scale offered 1 (lowest) to 10 (highest) scores. The majority of completed feedback addressed this item, even if other items were missed. Rating scores were overwhelmingly high. Nine people even recorded a rating of 10+, despite this not being an option. It is unknown if these nine responses are included in the figures reported here.



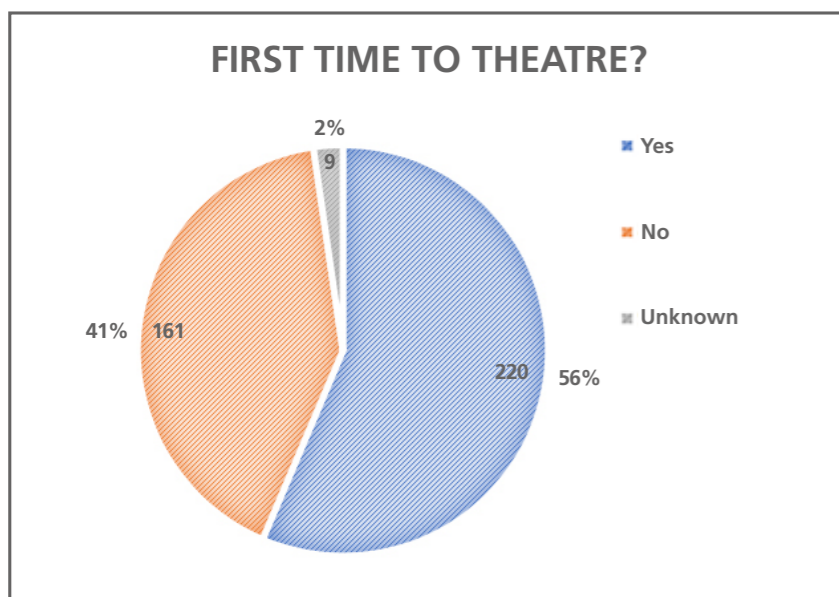
Rating	Number	%
Under 6	2	0% (less than 1%)
8 out of 10	9	2%
9 out of 10	28	7%
10 out of 10	368	90%
Total responses	407	

Nine audience members chose to write scores over 10 – above and beyond the rating structure

Previous history – two items asked questions about experience of the theatre

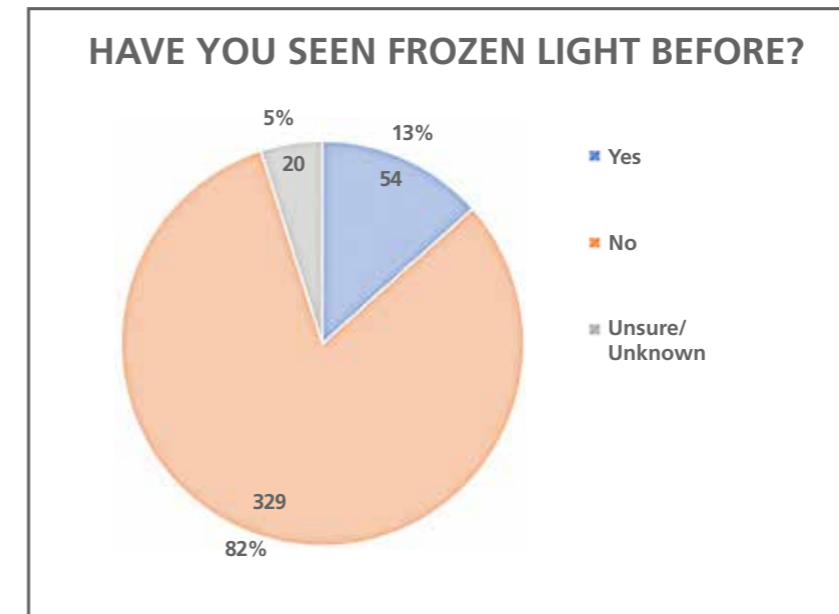
- 4. Has the person been to the theatre before?
- 5. Has the person seen a Frozen Light show before?

Not all respondents completed these items.



Previous attendance	Number	%
Yes	220	56%
No	161	41%
Unknown	9	2%
Total	390	

First theatre visits - Not all respondents answered this item.



Have you seen Frozen Light Before?	Number	%
Yes	54	13%
No	329	82%
Unknown / Unsure	20	5%
Total	403	

From reviewer conversations at ten shows, this information was frequently unknown by many staff supporting the people with PMLD; by contrast, family members were well informed if their relative had previously visited a theatre or Frozen Light show, even if this was undertaken by their school or another support provider.

However, it may be of note that of the ten shows attended by the reviewer, many audience members claimed to be first time visitors – to any theatre and to a Frozen Light performance.

Contact information

Audience members were invited to offer contact information

- 6. to join mailing list for future shows
- 7. to be contacted for further feedback

Additional comments were invited (open text)

These views and comments are discussed in the following sections of this report.

5b

PMLD Standards for Individuals: introduction to findings relating to outcomes for individuals

The experiences and outcomes of individuals with PMLD remains central to the purpose of this review. This section will consider the relevant findings from the views of the whole range of stakeholders together with first hand observations during the ten performances attended by the reviewer. Some of these observations focused on the artistic performance of *The Isle of Brimsker* itself, some on pre and post-show experiences, and some were simple observations of the responses of audience members with PMLD and how they were enabled to engage in the show by others.

The collated views were considered against the six Standards for Individuals from the PMLD Standards (Doukas et al., 2017). It is of note that some standards appeared to be more (or less) relevant to this particular focus on a theatre experience.

Stakeholder views

Each standard is reflected on separately in consecutive sequence as they appear in the PMLD Standards. Audience feedback and the views of other stakeholders are used to demonstrate the standards being evidenced, to highlight gaps in practice or where the quality and appropriateness of provision is in question.

Analysis of these findings identified both common threads and more unique issues. Many respondent comments offered reflections that readily applied to more than one of these standards; for example, standards relating to 'communication' and 'relationships' for individuals understandably shared a number of common issues.



Standard 1 Communication

Extract...

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.

PMLD Standards for Individuals - Standard 1: Communication (p28)

The concept of communication for this population requires we take a much broader view because modes of communicating and interaction styles will differ from the expected and the conventional.

The PMLD Standards highlight the issue of communication in particular as an essential element of the common characteristics shared by people with PMLD;

*'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 ...'*

[p12, text emphasis added for clarification]

The nature of differences and disabilities of this group creates a substantial barrier to their ability to communicate effectively. A very severe learning disability creates a very significant delay to their development (both cognition and communication) and impairs their brain's ability to process and make sense of any information they receive. In addition, physical and/or sensory impairments can impede how they receive information or express any response to that information. The significance of communication for this population is both explicitly highlighted and embedded implicitly throughout the PMLD Standards (Doukas et al., 2017).

The literature demonstrates that the role of a responsive 'care-giver' is fundamental to the early development of functional language and communication (e.g. Coupe O'Kane and Goldbart, 1998), in the first instance by actively viewing the individual as someone

who can communicate (and regardless of how). This care-giver or 'communication partner' helps shape communication understanding and skills, initially by acknowledging and attaching meaning to any and every response the 'early communicator' makes - whether or not it was made intentionally. At a later stage, this communication partner becomes selective and only recognises certain responses to be communicative and meaningful (e.g. a smile to mean a 'like' or a request for 'more', a head-turn or grimace to mean a 'dislike' or even, 'stop!'). Consistent and repeated experiences allow the early communicator to recognise these ways of responding and begin to associate that their responses can affect and have an effect, causing things to happen, until the individual develops the key milestone or concept of communicating intentionally.

In people with PMLD, their repertoire or vocabulary of expressions and physical responses may be very limited – in some, their ways of responding are barely visible except to those who know them really well. Examples of responses might include a tiny blink, a very quiet sigh, a wider opening of the eyes, a tongue movement, a change in breathing rate or even holding of breath; sometimes the person's only means of expression is created by a slight tensing or relaxing of their muscles that you would only detect if you were in physical contact with that person. One common response that is easily misunderstood is what appears to be 'no response' - the whole body becomes motionless, sometimes closing their eyes. However, it is more likely this is a 'stilling response' (a recognised reaction) and is a very valid and meaningful response. It can demonstrate at very least that someone *is* aware of the situation or the stimuli or interaction – or equally that it has stopped. For others it can simply be their way of cutting out competing stimuli (e.g. other sensory information that may be distracting) to enable them to focus on just one sense at a time, such as closing their eyes to listen or contemplate the temperature, smell or texture of an object.

Experience shows that creating repeated opportunities like those needed to promote early developmental milestones are extremely valuable for people with PMLD. In order to facilitate and promote communication skills and understanding it is essential that every opportunity is supported by the consistent approach of others acting as sensitive and responsive communication partners. Progress is most effective when the communication partner knows the person with PMLD well, as well as being familiar with their ways of communicating and interpreting meaning from their responses. Learning and understanding of the world for people with PMLD is mainly situation-specific (e.g. one person, a certain place or a particular activity or familiar event). The ability to respond and interact in less familiar contexts (ie unknown people or surroundings) demands confidence and greater application of skills (e.g. transfer or generalisation to the new situation).

Evidence of promoting Communication experiences

The Isle of Brimsker ~ the Show

Interactive approaches – giving people a ‘voice’

Frozen Light’s style is very much about reciprocal, two-way interaction; interaction as communication and interaction with the environment. It is clear from observing the performance that the whole theatrical experience centres around valuing people with PMLD for who they are; giving them a voice and by sensitive responding, some sense of control during this brief moment in their lives.

Although scripted, the show facilitates opportunities throughout the performance for people with PMLD to initiate and lead the direction and pace of travel that is most meaningful to each of them. So whilst one person may be directly interacting with one of the actors at their own pace, another may be expressing a greater preference to halt or even reject an invitation to interact.

Freya, a woman in her 50’s with a significant vision impairment expressed clear preferences to the range of sensory props offered for exploration. Some she responded to positively by tilting her head and ‘stilling’ her whole body as she contemplated the sensory features of the item (warm stones placed in her palm), others she rejected outright, swiftly and assertively pushing them away (grated ice in her palm). These contrasting responses may simply be reflex reactions and not intentionally made to convey preferences, likes or dislikes, but the actors valued each response as if it had meaning, resulting in Freya directing this experience.

Audience feedback universally commented on the positive opportunities for the person they were supporting to express themselves in whatever ways they could.

- Q Performers read the client’s body language and reactions to each stimuli and acted on this
- Q ...[they] made it personal to our students
- Q Nicky responded really well to the whole sensory experience
- Q MJ loved the song with her name in it, different lights & visuals and sounds & smells.
- Q Absolutely fantastic interactions and involvement with audience.

The use of structure

The storyline spanning the show was supported by the use of a clear structure, separating and signposting a number of dramatic and emotional elements. Music, song, variable tempos, actor narratives and dialogues and special sensory effects each punctuated beginnings and endings that made

up the chunks of *The Isle of Brimsker* story whilst also signalling change, something different, was about to happen.

These cues were a really constructive way to convey information to audience members, many of whom were observed by the reviewer anticipating those changes.

For example, a number of individuals with PMLD who chose to move about (out of their seats) during the performance, were seen to respond to such cues, returning to their seats – anticipating ‘their turn’ was approaching and then when seated, to communicate to the actors they were ‘ready’ to accept the sensory item being passed around or to enjoy the leaf blower aimed on their body.

Another example observed was when a distinct change in lighting and music tempo prompted an individual to look towards his carer - to acknowledge and share in this change and perhaps to seek reassurance.

Sensory props

Frozen Light made extensive use of props each with a dedicated sensory focus. Some concentrated on a single sense, others combined senses (e.g. smell and touch, vision and sound) alerting the audience members to take notice and explore its properties, hopefully prompting them to communicate a response.

- Q Stevie loved the vibrating pool and the ice shavings
- Q Luke just ‘came alive’ when the music started [for the storm] – really excited by that blower when it came near him – reaching up at the paper confetti
- Q [Kaya] tapped the tray of stones to get him to look. He pushed her hand out of the way and grabbed a handful- then dropped them on the floor – really noisy. [Kaya] laughed and that encouraged him to do it again – he was laughing too!
- Q Actors were excellent at interacting with the audience and encouraging participation
- Q Time spent with each individual meant every element was appreciated.
- Q An incredible experience, very sensory and inclusive, reading body language of the users and responding appropriately

The performers took these sensory props directly to each individual with PMLD, frequently looking to the familiar carers for a steer on the best ways or positions to present the items and get shared attention. The reviewer observed this sensitive personalised interaction in every show attended – seeing the performers checking out with carers whether it was OK to touch hands, stroke a face etc. This enabling approach made the difference from a prop or sensory sensation being a fleeting experience, done to the person to a human connection, to being a listening and responding that ensured this shared item held some interest and elicited an expressive response.



Agata (actor) offered the radio to Ahmed, its colourful lights flashing as it called out the ‘shipping forecast’- there was no obvious response from the young man. She moved the radio to different positions (to work out where he could see it best) until a subtle head move was seen. Agata prompted Ahmed to place his hands on the vibrating radio – immediately he sat bolt upright, his eyes widened, his mouth opened as if sharing silent words ... and then a smile evolved. He turned his head towards his carer, as if to share this moment. Ahmed’s hands dropped from the radio and his posture returned to a subdued place. Agata offered him the radio again, repeating the prompt to feel the vibrations – Ahmed repeated his expressive response in turn. Agata lifted the radio and held it to his face. Ahmed gave the biggest smile, raised his arms and ‘shrilled’ such a happy sound – sheer pleasure we suspect.

The performers welcomed each person with PMLD individually with a song using their name, sung in beautiful three-part harmony. To ensure the individual knew it was dedicated to them, the singing was in close physical proximity, with the actors touching that person at the start and close. One young man had become very anxious from entering the auditorium; he was visibly concerned at being in a strange place, in the dark and now, with strange and unexpected things happening around him. The actors began their song to which this young man immediately expressed clear anxieties – instantly, in response to this distress, they stepped back out of his personal space and intuitively dropped the volume and tempo of the music and singing until it was almost a whisper. The young man calmed a little ... until the singing stopped.

Approaches to support communication

Total Communication - a process that ensures that all forms of verbal and non-verbal communication are recognised, valued and actively promoted within an individual’s environment.

Gloucestershire Total Communication (2015)

The use of alternative and augmentative communication (AAC) approaches are an important support to the spoken word for people with communication difficulties. People with PMLD benefit from the use of multi-modal or TOTAL Communication approaches, particularly when personalised to meet their individual profile of needs (for example a physical disability, hearing or vision impairment). Their communication styles will be unique to each

person and will therefore require a different response to support and enhance it. Examples of support could include using non-verbal communication (such as exaggerated facial expressions and gestures to emphasise spoken language) or echoing an individual's own sounds, their gestures and postures or, by mirroring their unique responses as a way of acknowledging their 'voice' is important, valued and has been heard.

People with PMLD function within the early stages of communication development; many will be at the very earliest stage, where their communicative attempts are pre-intentional (sometimes their responses are simple reflexes and automatic reactions to stimuli), some will be communicating intentionally (i.e. they understand their communication has a purpose and can make things happen), and some will understand and perhaps use a number of single, key words (through speech, sign, picture, symbol or object). Understanding and use of language/communication is often situation-specific – so in specific familiar routines or with particular people, they may understand the simple language being used or may request familiar items; in new or less predictable situations, they may not be able to generalise this learning or understanding.

Using approaches to support the spoken word helps clarify meaning by offering additional information. There are informal and natural ways to do this (such as facial expressions, gestures, intonation of voice, enhanced attention on the environment or objects being used), and there are more formal, standardised modes, where particular objects, sign language, visual picture/symbol and tactile systems are used in an agreed way to represent and convey specific meaning. Accurate assessment by a specialist speech and language therapist (SALT) is key to making the right decisions for communication support. Wherever possible, a person's natural communication style needs to be valued and supported to be used, regardless of decisions to utilise other AAC approaches. Your voice or gestures are available to use anywhere, anytime; AAC approaches and devices like symbols or objects of reference may not be quite as ideal ... or portable – in a dark theatre, in the swimming pool or on the bus for example!

The Isle of Brimsker used sign language to support the spoken word (and song). The performers moved beyond signing single keywords to augment the storyline and add emphasis to the strength of emotions. This visible action also drew more focused attention to the person speaking, for the benefit of the audience.

'the signing is an interesting issue [to get right] – it's stimulating at the very least'

(Frozen Light team)

This feature, using sign language to augment spoken dialogue and song, was commented on by a few people watching the show, particularly some of the expert reviewers who were expressly tasked (by the reviewer) with commenting on potential areas of improvement

One support worker specifically commented on the importance of the actors using sign language to communicate the story for the man he was supporting;

'he absolutely loved the actors signing. He kept trying to 'tell me' – "signing – like me" [with gestures]. It felt this was such an important thing for him. He really sat up and took notice [mimes actions]. He doesn't see that very often [signing] from other people – especially outside his staff team'. When the topic was explored further, the support worker continued, 'the signs were...too complicated...for him – but you could see he was following the actors with his eyes... really trying to understand. That was such a highlight for him. It just never occurred to me how important that might be – seeing other people use sign [language] - like we do with him'.

(Support Worker to man aged 66)

An experienced Advocacy professional talked generally about the challenge of 'getting it right' when using AAC approaches, and specifically the use of sign language;

'...the signing was a bit quick...and possibly bewildering? I can sign but I couldn't follow it all. Almost like too much, too quick. I'd simplify – some repetition of key signs so people have the chance to grasp them?'

(LD Advocacy Lead)

Commenting generally on the use of approaches to support communication 'Intensive Interaction techniques [were] used through movement, touch, sounds – and everything else!', as a means of eliciting interaction whilst respecting an individual's natural communication style. Ideas for further development, especially for those with sensory impairments or at the earliest levels of communication development might be 'the technique of hand-under-hand support - to enable co-active signing', where the person with PMLD and the communication partner, co-create signs with their joined hands 'or the use of on-body signing', where the communication partner uses agreed signs / signals on the body of the person to alert them to what is about to happen etc.

(Advisor on Sensory Impairments / MSI)

'Acting - was very engaging with fantastic facial expression and eye contact. I did think there were a few too many signs which were done a little fast at times. Need to keep a core few that are visually different, easy to copy and used repetitively so people can join in'. 'Talking was a little fast and wordy at times but for many it would be the intonation and changes of pace that people would be tuning in to. Perhaps there could be more variation here. However too slow and you will lose the momentum and engagement'.

(Specialist LD Speech and Language Therapist)

Some aspects of the PMLD standard for Communication inevitably overlap with other standards for the Individual. Having a means of communicating that is effective - successfully listened and responded to - is key to every person's wellbeing. Communication is fundamental to a quality life, essential to every relationship and all engagement in activities being meaningful. As a consequence, similar perspectives and common themes will reappear in later parts of this Findings section.



Standard 2 Health & Wellbeing

Extract...

Each person's health and wellbeing are actively promoted and supported, to enjoy a full and long life. This will include ... a recognition of the holistic vulnerability of people with profound and multiple learning disabilities.

... [others] have an awareness of what good mental health looks like for each individual and will develop strategies to ensure good mental wellbeing.

PMLD Standards for Individuals - Standard 2: Health & Wellbeing (p30-31)

of over-shadowing (assumed part of their learning disability) and their communication difficulties - particularly when they experience such great barriers to express their emotions and basic needs (e.g. pain, anxiety or distress) (for example, Fergusson & Howley, 2015; Fergusson et al., 2008).

Within the context of the Care Act (England) 2014, the principle of Wellbeing has an intentionally broad definition which maps easily to the PMLD Standards. This definition specifies the following areas of care and support local authorities are required to address in their 'Duty of Care':

- i. Personal dignity (including treating individual with respect)
- ii. Physical and mental health
- iii. Emotional wellbeing
- iv. Protection from abuse and neglect
- v. Control by the individual over day-to-day life (including care & support and the way it is provided)
- vi. Participation in work, education, training and recreation

Frozen Light's performance of *The Isle of Brimsker* and indeed, the broader theatre experience all contributed to, and impacted on, the wellbeing of its entire audience, but of people with PMLD specifically, by addressing the areas listed above and those described on the PMLD Standards.

The findings section for Communication has previously highlighted the positive contribution of the approaches adopted by Frozen Light. This strongly evidenced individuals being valued, heard and responded to. There were opportunities throughout the performance to express their interests and motivations, likes/dislikes and even a sense of control, by indicating the pace and style of engagement they preferred. Each of these examples clearly show influences on wellbeing being used in a constructive way.

This review found further evidence mapping specifically to certain indicators of Standard 2: Health and Wellbeing for Individuals.

Emotional wellbeing and positive mental health

Most examples of audience feedback referred to people with PMLD experiencing positive emotions to the show (such as presented in the previous section) – how much they liked, loved, enjoyed certain parts of the performance. Further scrutiny revealed comments that used broader subjective language and qualitative descriptions indicating emotions and wellbeing more generally. Interestingly, some views appeared to be written with empathy and apparent understanding – perhaps written to be interpreted as *'I felt this, so believe you might feel the same way'*.

The Constitution of the World Health Organisation offers a valuable, holistic definition of health:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

(www.who.int/about/who-we-are/constitution)

Fundamental to the profile of this population is the presence and compounded effect of multiple impairments or disabling conditions and/or complex health needs. As a direct consequence of the inter-relationship of their multiple conditions (may include for example, physical disabilities, vision or impairments or sensory processing difficulties) and strong evidence of health inequalities, people with PMLD are 'holistically vulnerable' and at greater risk of their health and wellbeing status being compromised. They are completely reliant on others to constantly monitor and actively support their holistic wellbeing (LeDeR, 2019; Doukas et al., 2017).

People within the wider learning disabilities population are recognised as being up to six times more likely to experience mental health concerns during their lives than the general population (Emerson & Hatton, 2007). The mental health and emotional wellbeing of people with PMLD may be at even greater risk, too often overlooked or under-diagnosed because

- Q *Very relaxing and calm. Leaves you feeling happyand him too??? Thank you :)*
- Q *I loved the atmosphere, the way the characters interacted and sang to the audience, lovely story, beautiful harmonies. How do you make hot shells? Thank you!*
- Q *Absolutely amazing show pupils were so focused, engaged, quite emotional to see*
- Q *Such an amazing experience for my daughter, like a sensory story on steroids! In the nicest possible way....*
- Q *We had an absolutely brilliant time ... Rothko thoroughly enjoyed himself*
- Q *Incredible. Interactive and awesome. I didn't like it, I absolutely LOVED it*
- Q *2 thumbs up. Lots of claps*
- Q *Amazing. Never seen her so calm.*
- Q *What a fabulous experience ... Callum is a shy... but grinned throughout*

'As we came in to the space I was worried that the unfamiliar environment could be troubling to some, but as the performance started, I became swept up in it myself. Cocooned in my private booth of transparent, iridescent fronds I marvelled at the strength of the acting'. '...the acting has a purity to it that makes it incredibly powerful.'

(Sensory Engagement & Inclusion specialist)

'He did really well. He was a bit anxious about the sounds- the live music, the first time the actors sang at the front and then the radio – but he managed, we didn't need his ear defenders. When the actors sang the name song to him, he did look up – and had a smile for them!'

(Keyworker, supporting a man in his 50's)

'...it was exciting, and very moving at times, you clever, clever people. The story is magical, and you use such clever little tricks to bring it to light. Loved so many bits - the beautiful smell that wafted out as we were waiting [outside the auditorium], the blankets- nothing more comforting than being wrapped in a gorgeous warm blanket... [it] smelt divinethe cosy space you created seemed to make everyone feel relaxed on arrival. I just revelled in each tiny bit ...'

(Service Manager: Activities for adults with PMLD)

'...the actors came round, they interacted with each audience member – this made it very personal and an overall better experience'. 'The space [auditorium] was on the small side - but this made it even more comfortable...'

(Drama Student)

'I liked the storm where the actors sprayed water on us and there was paper blowing around - so it felt like a real storm - and it felt really magical. I can still smell the spray that was golden syrup and toast. I really liked all the smells, the rock pool ...the vibrating rock pool was calming'. 'We could see the lady next to us really liked the play and she reached out to me and took my hand – and she got me to shake her friend's hand too.'

(Phoebe, aged 9 – family member)

One reviewer commented specifically on how the show, and the performers' abilities, created a variety of atmospheres and mood changes,

'...sounds varied in volume, rhythm and sound quality – following and leading the story from gentle to shouting, quiet to loud, crying to laughter, staccato to flowing etc...'

She also commented on the respect and human connection between the performers and their audience members,

'Actors used their voices individually to talk [to audience with PMLD] and support staff – warm, smiling voices, supported with touch. ... Communication through intensive Interaction techniques using touch – the person [with PMLD] uses fingers, actor uses fingers building to a conversation.'

(Advisor on Sensory Impairments / MSI)

The individuality of the audience members with PMLD was always central to the Frozen Light performance. The challenges of sensory processing difficulties (the brain's inability to 'understand' and regulate sensory

A profound intellectual disability means that an individual experiences significant delays to learning across all domains, including social and emotional development. People with PMLD likely have a poor awareness of themselves, let alone other people. Their disability-related differences and limited opportunities to participate in their local communities mean this group continue to be amongst the most marginalised and isolated in our modern society. The impact of this further restricts their life experiences and chances to continue to develop fully as a person and as a social being.

Reflecting on the impact of *The Isle of Brimsker* as a catalyst to elicit emotional responses, one of the expert reviewers commented,

'A typically developing [person] has ...opportunities to meet themselves in stories and experience drama these are key to the development of an understanding of self, instrumental in understanding the world - both the world outside of ourselves and the world of emotions within us... Involvement in the arts is good ... for mental wellbeing and their development as citizens'.

This show, a dramatic piece of theatre, encouraged the individuals with PMLD to move away from the routine and the familiar, to bravely open themselves to the novel and the challenging, but with the backup of some creature comforts and security of familiar carers close by. During dialogue with the 'expert reviewers' some specific features of the show were highlighted as creating opportunities to experience the wide range of emotions within this brief moment in time. As previously questioned, a subjective interpretation of their views offered echoes of compassion - empathic assumptions perhaps?

'Flo Longhorn (world renowned sensory guru) advises us to throw away all our assessments and look for 'golden moments'; a speech therapist on TV said she was 'chasing the smiles'. The performance I attended provided a host of golden moments - and smiles. I moved my chair so I could see their faces better'

(Multisensory Activities specialist)

information and sensations) experienced by some individuals was a constant on their radar, responding with respect and acknowledgement that each individual had unique needs and that these needs changed minute by minute.

'We are usually asked to sit quietly in our seats at the theatre, and this can in itself exclude many people with learning disabilities. However, at a Frozen Light performance, the audience can move around and express themselves in a way that is not just tolerated but is actually invited - and becomes part of the show – brilliant!'

(Health and Wellbeing Programme Manager. LD care provider)

By contrast, the reviewer observed a less positive experience for one woman.

At an incredibly busy London venue (a repeat visit by Frozen Light and show numbers 3 and 4 for that visit) the box office appeared to be surprised when the audience, people with PMLD, began to arrive. There was much confusion about where they should wait and when the show would begin. The shows advertised for that day did not show The Isle of Brimsker in its billings.

I saw a woman with her carer – quite visibly searching out the quietest space in the foyer, away from the incredible noisy bustle of Saturday morning kids' drama classes. I went over to join them and chat about The Isle of Brimsker. Freya, a woman in her mid-fifties was beginning to look agitated as the sounds bounced around the hard architecture of the modern theatre; she rocked forcefully in her wheelchair. Her carer told me Freya was blind and hated noisy places ... like this. She had supported Freya for almost twenty years but neither of them had visited this theatre before (or any other theatre) – they were both unsure of what to expect. I offered reassurance but my chatting on top of the ambient noise levels was all too much for Freya and she began to self-injure. I suggested my presence was adding to her anxiety and moved away, giving Freya space and less auditory stimulation to calm herself.

Disappointingly, despite the support, guidance, information and face to face briefings the Frozen Light Team offered to every venue, some theatres chose to forgo or ignore this insider-knowledge and advice. As a consequence, the experiences of people with PMLD were sometimes shaped by the lack of care and attention to detail by the venue staff on what may be a first and only visit to a live arts performance in a public theatre. Addressing simple, reasonable adjustments can make the world of difference to shifting a negative to a very positive experience - in Freya's case, for example, by providing a quiet and more appropriate waiting area.

The Isle of Brimsker experience was noticeably challenging for a number of people with PMLD, particularly some of the older adults. It is valuable to reflect on why this might be? People aged in their 50's and 60's (and younger) may have spent years of their lives in long-stay hospitals and institutions, often tucked away in rural locations. They grew up before the legal entitlement to education for people with learning disabilities was introduced in 1970's. Unlike the younger adults in the audiences (many

still of school age) who have a greater community presence and visibility and whose lives have been more varied (relatively speaking), it is probable the older group had far narrower life experiences. They are more likely to have missed out on many of the specialist strategies and approaches used by Frozen Light, (Intensive Interaction, multisensory activities etc) – and even, having their voices 'heard', or having a sense of control in their own lives. Their life experiences are likely restricted further when considering opportunities to participate in their communities or accessing live theatre.

Medical and health needs

Many of this target audience experience complex and life-long health conditions, and some are dependent on technology to manage their medical conditions (requiring oxygen, for example).

The reviewer met Connor and his parents before one show. He was a regular theatre-goer but this was a first Frozen Light show. His Mum commented on Connor's over- excitement getting 'too much' and he started to have an epileptic seizure. Within an instant his Mum responded, she passed a medical stimulator over his neck and he visibly calmed. [Under his skin here was an implant that when stimulated helped regulate electrical brain activity and controlled seizures - Vagus nerve stimulation therapy]. Shortly after this, Connor was fully engaged in The Isle of Brimsker performance.

One audience at another venue comprised a school group of young people with PMLD. At different points during this show, five of the six audience members were observed having some medical intervention. These procedures included administering medication, deep oral suction (for those with swallowing difficulties), gastro-feeding, manual and pump-feeds via PEG and MicKey button (through the abdomen). In most cases, the individuals were quickly able to resume their participation and enjoyment of the show.

For these individuals, such essential medical procedures are part of their daily routines – regardless of where they are or what they are doing. Observing these needs being met in the auditorium with such acceptance was a real plus as a family carer myself.

Standard 3 Meaningful & Quality Relationships

Extract...

A sense of belonging is a vital element of the person's quality of life.

The person is empowered and enabled to do things ... to develop and maintain positive relationships (in their own home and beyond).

PMLD Standards for Individuals - Standard 3: Meaningful, Quality Relationships (p32)

In the main, relationships develop and become established over time, especially those relationships that are of any worth. Getting to know someone and how to 'be' and interact with them is key to developing trust and feeling comfortable in their presence. Most of us can decide to spend time with our families, choose our friends and form different relationships with people we work alongside or become acquainted with. Such opportunities for people with PMLD are greatly reduced and within the control of those caring for them.

The reviewer met a number of families who had come to *The Isle of Brimsker*. They welcomed the rare prospect of joining their relative with PMLD in a mutually enjoyable occasion – particularly as this person had grown older.

George and his Mum had come to the theatre with his school group. She told me they only ever went to sports events -this was a first. Watching their mutual pleasure through the show was a delight. After the show, she volunteered how much they had enjoyed the show - 'so lovely to share this with him. Now I've been [to a Frozen Light performance] I'd happily bring him on my own next time.'

At a weekend show, I met three young people with PMLD who came with their Mums and assorted siblings. The three young men were at school together and their families made great efforts to get together outside of school to nurture friendships. Their parents explained the challenges of finding 'activities'

that included them, let alone were designed specifically for them – 'usually, they are just parked on the side-lines, watching everyone else have fun. This is the other way around – it's fantastic. We are on their [Frozen Light] mailing list – we need to make sure we get enough tickets to come together!'

The literature presents some stark figures around 'friendships' for those with learning disabilities. Parry-Hughes (2011) reports on research into this topic and finds evidence that only 38% of adults with PMLD saw a friend at least *once a year*, compared to 66% of all adults with a learning disability and 92% for the UK population in general. However, the broader notion of 'connecting' is a more valuable view since *'quality of life is influenced not solely by friendships but by all relationships and the essential opportunities and right support to develop these essential social connections'* (Fergusson, 2016, p31).

The concept of a 'circle of support' is an often used model to capture social networks and the range of potential relationships within a learning-disabled adult's life. Those with closest bonds (usually family or key-worker) will be in the inner circles; moving to outer circles will be those who are less familiar (perhaps therapists, for example) and even acquaintances (someone from the local shop or a neighbour perhaps). Within an individual's social network, aside from their families (if indeed they have any family in their lives), the main experiences of relationships for many people with PMLD are likely to be with those paid to support and care for them. Nonetheless, such relationships are crucial and can still be extremely meaningful and reciprocal.

Opportunities for people with PMLD to develop any quality of relationship during a one-off, one-hour performance were not an expected outcome. Yet this theatre experience was an interesting context in which observing relationships could not be avoided. The role of 'companions' was as diverse and unique as the audience members with PMLD. Some people were supported by family members, very familiar keyworkers and personal assistants who knew the individuals with PMLD really well; some were assisted by less familiar, less experienced, less interested 'others'. The quality of care, interaction and support was a clear indicator to the quality of the relationships – impacting also on the quality of engagement and participation in the theatre performance by the person with PMLD.

One expert reviewer specifically commented on the quality and variable enabling that companions offered to the person they were supporting;

'... I wonder if some verbal information could be given to support workers- to remind them it is interactive and relaxed...'

'Good use of props to engage people, unfortunately not all support workers were encouraging engagement at this performance even though it was relaxed and anything was encouraged.'

'...the actors told me that they had considered the fact that some couldn't eat but were allowed to smell and that they relied



on info from support workers about which experiences to avoid with individuals. Using audience movement and more obvious encouragement to join in at the beginning might help some of those support workers warm up and be a little more engaged. Sometimes I think they got caught up in the script and play, leading to ignoring the person they were supporting until the objects were brought [directly to individuals with PMLD].'

(Specialist LD Speech & Language Therapist)

When interviewed, each member of the Frozen Light Team spontaneously commented on the approaches of 'companions' who were there to support and enable the individuals with PMLD. For example, one member mentioned a regular feature of their post-show debrief was identifying positive reactions from the audience and reflecting on how people were supported – or not. When asked about possible challenges they had experienced as part of the show/tour, a member of the team spoke of the differing quality of interaction and respect people received from their carers.

- Q 'when a blink is the biggest reaction they've noticed [from the person with PMLD]what is the rest of their life like?'
- Q 'for some people it's clearly one hour of real connections – connections to other humans, to the world ...but what happens next?'
- Q 'we always look to the carers – to ensure we find the best, the right ways - of connecting ... engaging with the person [with PMLD]. Some folks so naturally indicate or show us what they are OK with – sometimes they offer to try the experience themselves first, to reassure the person [with PMLD]. Like the grated ice – they see their carer shriek at the intense cold – they think it's hilarious!'

Team members were asked what they thought worked well about *The Isle of Brimsker* and the Frozen Light approach;

- Q *Personal attention*
- Q *Giving audience members time and attention, that they are valued human beings and can enjoy the same things as everyone else.*
- Q *Al [musician] gives them a way in – he brings his music to them, in their personal bubble; in every show, it's the music and the singing that 'get through' – singing their own name to them is usually what connects us – knowing they enjoyed it really matters*
- Q *Seeing the joy you bring to someone's life and their families*
- Q *Someone who turned up with their WHOLE family – it wasn't everyone's thing (Grandpa hated it) ...but they all cried at the name song*
- Q *Whoever you 'reach' – you brighten their life – it's all about the people*
- Q *The close-up interaction – it's a defining feature; the closer we get, the better we connect ... then it's rewarding for you both'.*
- Q *Best bits? Getting a family who come 'prepared' as we plan it – they got the pre-show information, they share that together and get excited together - then they enjoy the show right from the start.*

Standard 4 Social & Community Life

Extract...

Social and community life is about thriving not just surviving.

People are 'visible' and actively involved in their communities and activities they do; they are not passive recipients.

**PMLD Standards for
Individuals - Standard 4:
Social & Community Life (p33)**

first smile; the reflex head-turn to locate someone/thing that moves across our line of sight as a potential protector or foe; the mutual gaze of infant-caregiver or gaze-coupling, a precursor for later turn-taking as a fundamental skill to interaction and 'conversation' (e.g. Nind & Hewett, 2005; Dutton, n.d.). Babies in general have large eyes to visually appeal and draw in connection with their caregivers and trigger the bonding process (in many species it seems – think also puppies, kittens, etc).

Important early development of functional language, social skills and communication is shaped by the people around us, who interpret our reactions and spontaneous responses as if they had meaning and responding to that meaning. It is this process of attaching of meaning by others that leads to it becoming meaningful and intentional communication (e.g. Coupe O'Kane & Goldbart, 1998; Doukas et al., 2017). A pre-requisite of intentional communication is being able to act intentionally first – knowing that what you do makes things happen and taking this action. Another early stage of communication is the young child's *reach for* signal – literally using physical gestures to signpost *another person* to get what they want. Without the active listening and responding of others, these early learning skills will be restricted or even never developed. The significance of the role of others, especially as communication partners, is discussed in more detail previously in this report.

These relationships continue to be central and important in most people's lives through adulthood as well as childhood. Our needs to be connected with others are lifelong needs, not solely for early learning, so too is our potential to continue to learn and to learn to achieve and thrive (Maslow). For those with PMLD, they are reliant on being given the right opportunities and right support and where these are driven by the high expectations and aspirations. Familiarity nurtures trust and security, usually given by families in the first instance. Other relationships develop over time as individuals experience increasing opportunities to meet, interact and enjoy the company of others, whilst learning social skills, maturing emotionally and developing resilience. As personal interests develop, there is a natural tendency to gravitate to like-minded peers and the notions of being part of a group or community to share the mutual pleasures of such activities.

Spheres of belonging

When considering the significance of social inclusion to the quality of life, it is important to understand the social networks or 'spheres of belonging' open to individuals with PMLD, and more especially, adults with PMLD. As people move through age phases, their spheres of belonging reduce and opportunities to access and be a part of communities shrink. The biggest factor affecting change is the move from child to adult services.

Individuals with PMLD aged 0 to 19/25 years – Education and Children's Services

Social contexts for learning about the world

We are all inherently social beings. When we question our own life purpose or what is most important to the quality of our lives, most commonly these outcomes are based on our connections to other people – our families and loved ones usually being our priority and our purpose, which is about making a difference to others. Consider life without those crucial, life affirming associations.

Our understandings of the world around us are given meaning through social interaction, and those inherently human connections with others enable us to develop the essential skills we need to engage and act within that world. Maslow's Hierarchy of Needs (explored earlier in this report) suggests that, in order to have fulfilled lives and achieve our potential, we need other more fundamental needs to be met as the foundation for progress. Our basic needs for survival form the base of this hierarchy, followed by social relationships and a sense of belonging before we can even contemplate a life of meaning or purpose. And yet we must consider that, for people with PMLD, their disabling conditions necessitate co-dependency – they are reliant on others to facilitate and enable them to achieve and progress at every level.

Typically, infants are hardwired with innate survival reflexes that seek and respond to people, and much typical early learning takes place within social contexts in order to meet basic and personal needs. Examples of such early learning includes: the rooting reflex to find nourishment; the significance of the



Most individuals will live with their families, growing up in the family home. They have an automatic sense of belonging to their family group, usually extended to include significant others, friends and neighbours and the local community by association.

They will attend some form of educational provision for most of this period, with care and support given by others in an educational setting. Following any early intervention, they usually move on to a school setting, where for a large part of their growing up they will be included (again automatically) in numerous groups and the school community by right. Such social connections will likely include for example, a class group (with their peers and a familiar staff team), subject groups and special interest clubs (e.g. Riding for Disabled, therapy-based groups, school council, drama or orchestra), youth or after-school clubs, and groups who join together for special events – school performances, residential trips and holiday playschemes. Opportunities like these are an integral part of school/college provision and extra-curricular activities.

Individuals with PMLD aged 18 and over – Health, Social Care and Adults Services

By law, certain entitlements change on reaching the age of 18 years – issues of consent and access to services (and funding streams) more specifically. For this group the relevant issues that influence their ability to be or stay connected socially and with their communities are the transitions that occur around

this age onwards. As people move on from education provision in to adult services, there is a greater risk of becoming less connected and more isolated, initially simply by losing their established social networks from school or college communities aged 19 (or at 25 years in some instances).

At some point, adults with PMLD *will* leave the family home and away from the direct care and support of their families that they had for the whole of their lives to that point. They move out of one sphere of belonging (extended family and neighbourhood) into a new sphere, where they are supported by paid carers in a new neighbourhood. Whilst the possibility of developing new networks exists, the literal nature of this transition means they have less contact with their family members, or in some cases where ageing parents have died they may no longer have a family to belong to. Some adults with PMLD may even have grown up completely apart from their families. In the 1950's, 60's, 70's and even 80's, it was still common practice for those with the severest disabilities to be placed in homes, long-stay hospitals or other 'care' institutions often in rural, remote and very isolated locations. Families were routinely discouraged from visiting. Although part of an internal community many of these adults were simply removed from sight, never leaving the grounds of these places let alone forging inroads or relationships into their local communities. In recent years however, most adults with PMLD will be living in more conventional housing within established local communities.

Post-education, adults with PMLD will have left behind full-time daytime provision (for most of the year). Here this population will experience the biggest change and contrast in their social connectedness and inclusion, literally overnight. The combined impact of mainly low expectations, inadequate funding and scarce local adult services result for many in a dearth of opportunities for meaningful engagement, for social networking and for any sense of citizenship.

Austerity cuts and the 'modernisation of day services' in social care led to the closure of many traditional day centres for adults with learning disabilities, including those with PMLD. Whilst this transformation was often very successful for their more-able peers because it offered potential for more interesting and creative options, it was not always so for individuals with PMLD. This group routinely need access to a familiar place, where they feel secure and that they belong. They also need adaptations in their environment to meet their everyday needs where 'comfort for living' can be achieved (e.g. Changing Places for personal care, facilities to access modified diets or specialist equipment, space with alternatives to wheelchair or supported seating for the management of postural care). They need access to staff skilled to empower them in specific approaches and techniques to enable interaction and for access to engagement (e.g. intensive interaction, supported decision-making, therapeutic interventions like physio regimes, sensory integration/sensory diets, on-body signing). Ideally, they require 1:1 and small group working, where they can interact and develop relationships and friendships with familiar people. These give the potential to nurture social confidence, to have a voice, to assert themselves and for reciprocal communication. They need activities that bring the world to them and stimulate their senses, where they have opportunities to share in joint-attention and enjoy taking turns with others. With repeated exposure to such opportunities they can develop the confidence and skills to transfer those skills to new social exchanges, in new spheres of belonging, where they are actively contributing to local community life.

In reality, the social care packages of many adults with PMLD supports activity outside of their homes for merely a few hours a week – *possibly* at an activity base (shared with peers) or, more frequently a handful of brief solo activities scattered across the local area and spread randomly over the week (or an even less frequent cycle). Without a base or place to go to regularly, to share in mutually-enjoyable activities and feel part of a group, individuals with PMLD quickly lose that sense of belonging; they very rapidly become disengaged and isolated. Fewer opportunities to develop friendships and share meaningful activities with others leads to the loss of any purpose to their lives, and it results in people spending more solitary time at home. This diminished community presence reduces the visibility of people with PMLD in local communities, and consequentially their low profile further compounds their invisibility from the responsibility and accountability of community and service providers, who see no needs to be met.

As a result of such lived experiences, the situation for some adults with PMLD is one of isolation and disengagement. It is understandable that some individuals are no longer familiar (or comfortable) being in the company of others, with few opportunities to use and maintain their skills - of interaction or to engage in interesting activities. Rather than actively seeking and appreciating social interaction, they may even prefer to withdraw to the familiarity and predictability of self-stimulation or the comfort of solitude. We must question – what quality of life?

People with PMLD will always have high support needs, they will always need others for their care, but equally they need others to create the opportunities Maslow speaks of, to fulfil their potential, to enable their access to the world and to support them to build meaningful relationships. Families care for their loved ones 24/7 often for a large part of their lives and frequently with little or no external support. The best examples of practice when they move out of family homes and into the provisions of social care, are where social care providers work in active partnership with families. Together they ensure individuals with PMLD continue to enjoy an 'ordinary' family life (an entitlement detailed in the Care Act, 2014) and just as you or I expect, but also to forge new connections, where they are supported to become accepted and included in their neighbourhood, participating in activities within the local communities in which they now live.

***The Isle of Brimsker* – exploring community participation.**

Frozen Light expertly combine a balance of approaches and techniques to build a community with their inexperienced audience members, in every performance of *The Isle of Brimsker*. This starts with their direct 1 to 1 attention to each individual with PMLD, offering them a safe place to begin this collective theatrical adventure. Each audience member with their companion is met in the foyer before the show by an actor and the musician – they are warmly escorted into the theatre auditorium with their own gentle, nurturing serenade. Once seated, a warm aromatic blanket joins the familiar pair together, then a personal glimmer-curtain- shelter envelopes them in their own dedicated safe space, cutting them off from the outside world and the remainder of the audience. The early part of the narrative either takes place at a distance (on stage) or is brought to them, into their own safe place. Performers and audience pairs interact in this secure microcosm within the auditorium space. Individuals are overtly valued and respected as individuals through very human and literal physical connection. The performers actively encourage and enable engagement in the story, the act of participation by audience members with PMLD is acknowledged as their significant contribution to this performance.

As the performance progresses, the audience are encouraged to move out of their own sheltered space, to join others on stage enjoying the sensory sensations of the rockpool – bubbles, mist, vibrations

and fountain splashes. At this point, people become aware of others sharing this space – their sounds, their movements and the spoken commentaries and whispers of their companions. It becomes clear they are no longer solitary beings on this island. Shelter curtains are drawn back and for the first time, the seated audience become connected – a community living the novel extravaganza of this theatre together. The remainder of the performance is experienced as a collective - right through and beyond the finale, where performers and audience members mingle in celebration at the mutual achievement from this shared journey. Audience members and their companions clamour for photos – to capture evidence of participation and contributions but equally, as important mementoes and reminders of this communal pleasure.

When considering the findings with this focus of social and community life, the audience feedback offered little that was directly related – rather their views concentrated on this opportunity for accessible participation and achievement as individuals because such opportunities are so rare and so clearly valued;

- Q *Such an amazing way to bring theatre to our PMLD young people. We travelled one and a half hours to see you and I thoroughly enjoyed seeing my son included, taking part and experiencing something he wouldn't normally be able to tolerate. His quality of life has improved just by being here - and I know he matters :) [emphasis from parent]*
- Q *It was helpful being informed of the performance through my daughter's school - otherwise I wouldn't have heard about it. Thank you.*
- Q *Loved it! Thank you so much. Lovely to see people who understand our students*

Almost all the expert reviewers were attending independently of an adult with PMLD. For this reason, they were perhaps able to see a wider perspective, of people with PMLD both participating as individuals and as a part of the whole audience during *The Isle of Brimsker* performance:

'It was only when I came to pass my balloon on to the person beside me that I looked up and saw that they too were caught up in the wonder. I looked around the room. Here we all were as equals. People with profound disabilities, carers, parents, boyfriends, fathers, mothers, brothers, sisters, care workers, teachers, and even sensory engagement specialists - all of us together, caught up in the sensory wonder momentarily occupying The Isle of Brimsker.'

'The chance to go to the theatre is not a frivolity of life, it is an opportunity to have life enriched, to develop and connect. People with PMLD of all ages are notoriously socially isolated, the chance to be included in theatre is joyful for them - and restorative to those who care for them who also suffer the burden of that social exclusion.'

(Sensory Engagement specialist)

'The show was full of quality from beginning to end. The standard of musicianship was excellent and the understanding the actors had of how to entice and invite the audience into the story, demonstrated a real knowledge, that we can all learn from, of how to be, around people with PMLD, in order to help make their world more interesting, participative, stimulating and real.'

'Well what can I say, The Isle of Brimsker was quite simply the most inspiring example of how to engage with and entertain people with PMLD in a way that absolutely values them, as paying audience members and as fellow citizens.'

(LD Health and Wellbeing Programme Manager)

'... during and after 'The Isle of Brimsker' by Frozen Light Theatre ... I felt connected, immersed, and somehow, full. Was this a 'show'? It felt (there's that word again) more like an experience; something that was more than just in-front of me but captured me and other audience members in a wonderful dream...

'Six people lined up in the front (and only) row and were instantly immersed in this experience; an almost fairy-tale story of what comes of our thoughts when left alone and how the world changes when we experience things together. It was fitting as the six audience members were gently guided into the story and the space between stage and spectator disappeared and we all became one.'

Sounds, light, touch, vibrations, musicianship and just great performance combined to tell a story and define an ambience that brought people a mixture of emotions as the tale was told. The story was literally brought to people.'

Supporters and carers scrambled to take photos and capture expression and delight on video. This, at first, threatened to overpower the performance but I quickly realised that the motivation to do this came from the right place: an excitement to see people take part and an urge to 'show' others what it was like. Perhaps the scramble will calm once we learn our lessons and apply more of this creativity in people's lives, not as a 'treat' every now and then but as seamless everyday way to value people's place, and contributions, in this (our) world. I urge others to go and learn (and feel) too.'

(Head of Involvement and Engagement, LD care provider)

'I have nothing but respect for the thought and experience that has gone into the production and I feel that anyone who works with, lives with, or is friends with someone with PMLD will benefit enormously from being at a Frozen Light show. I very much hope that we can do some work together in the future around motivating and inspiring the many people supporting those with PMLD - to bring the kind of quality and richness into their lives that I felt whilst on The Isle of Brimsker!'

(LD Health and Wellbeing Programme Manager)

Standard 5 Meaningful Time

Extract...

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

PMLD Standards for Individuals - Standard 5: Meaningful Time (p34)

The PMLD Standards indicate clearly the person-centred nature of understanding what is enjoyable, meaningful and fulfilling to an individual with PMLD. Just as you or I, they too may prefer to spend their time in different, often contrasting ways – sometimes actively, another time passively, perhaps being social or in solitude. The crucial factor here is that the person with PMLD has some influence over these situations, even if not directly selecting themselves. It is important that a person's interests and preferences steer the opportunities they have, in how they spend their time and who they spend that time with.

The PMLD Standards suggest factors of 'success' will indicate the person with PMLD *actively participating* or *being engaged* in activities that stimulate and interest them, whilst also being 'supported to experience new or different activities and events' (p34). The concept of engagement and participation for this population will almost always involve others in some form, empowering or offering enabling support.

People with PMLD experience huge barriers to understanding and interacting with the world around them due to their combined and complex needs of comprehension and access. These create demands and challenges for those designing activity and experience opportunities, tailoring them to be both meaningful and in an accessible format. From a pragmatic perspective, low or fluctuating levels of arousal and fleeting attention are common issues in this population, often making engagement problematic. These are often the pervasive side effects of medication but may also be a feature of their very severe intellectual impairment and the very early stage of understanding that they function within. However, these obstacles to engagement may equally be caused by fatigue from the physical efforts of movement, difficulties regulating sensory information or the actual process of concentration itself.

Understanding engagement for people with PMLD

Levels of engagement vary between people with PMLD and situation by situation particularly when comparing familiar experiences to those that are completely new or unexpected. Viewing these actions as points on a fully inclusive continuum of engagement helps us to adopt a positive view of individuals with PMLD (QCA, 2009, cited by Fergusson, 2016).

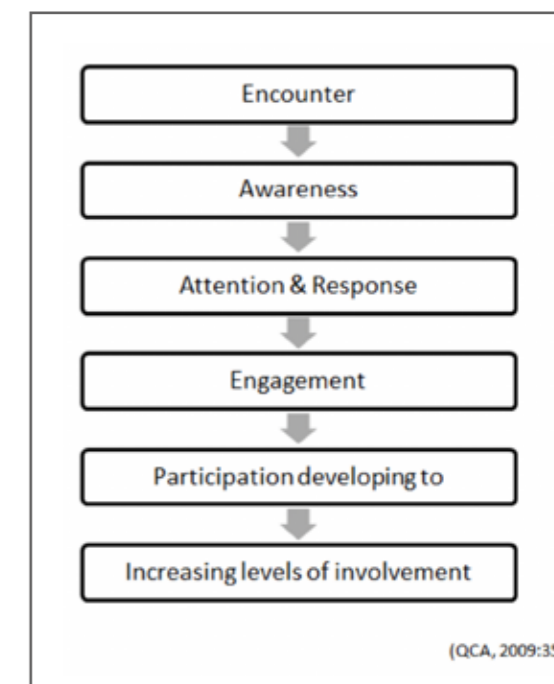


Fig 1: A continuum of engagement

Using this tool for reflection enables us to observe different levels of engagement for a diverse group of individuals and their responsiveness across a variety of contexts. In turn, this measure enables practitioners to reflect on the factors that may influence or inhibit greater levels of engagement and responsiveness for each person with PMLD (Fergusson, 2016). It is expected that prompting or even full co-active support may be needed at each level of engaging.

At one end of the engagement continuum is the inclusive description 'Encounter' which means every person, regardless of ability or disability, will be included at some point within this spectrum. Encounter describes a situation where an individual may simply be present within the activity or experience, often with little or purely reflexive behaviours visible despite full physical prompting and support from another person; there is no tokenistic assumption made of how they experience the interaction, activity or situation. This continuum spans progress and incremental steps through to levels of full participation and true involvement. Each place along this continuum is of equal value but different – and unique to each person. An individual will tend to move their place along the continuum according to each situation and even, move moment by moment.

The ability to be able to move along the continuum of engagement and involvement is influenced by many

factors. Internal or ‘within-the-person’ factors are only one element of influence over how meaningful or accessible an experience may be. Disabling conditions play a part - for example, the impact of limited movement, vision or hearing loss or the ability to filter and integrate information coming through each of the senses simultaneously. Wellbeing is another crucial factor that inhibits or enhances the experience for people with PMLD. If you are feeling uncertain or even anxious about a new situation (fight or flight), the physiological changes in your body limit vital capacity to understand, respond and engage (for example, blood flow to the brain and extremities are restricted, cognitive function is impaired). Similarly, if you experience things that interest and stimulate you, this fires activity in different parts of your brain and raises your arousal level and ability to engage.

External factors to levels of engagement, such as how the person’s interest and arousal levels are raised or how access is facilitated, have a hugely influential bearing on the outcomes for people with PMLD. Experiences need to be perceivable (salient and experienced through action and/or the senses), meaningful and motivational. What this experience is, how it needs to be presented and ultimately how it is received will be unique to each person with PMLD. Fergusson and Brookes, (2015) suggest a simple tool to prompt reflection and inform planning for next steps. Their PARTY prompt is described as a suggested tool for future use, later in this report. These factors highlight the keys to ‘success’ ... but clearly, there is no single straightforward formula.

Neuroscience and MRI technology demonstrates that the brain’s response to positive, motivating experiences continue for a time beyond that initial experience and can support new experiences, new learning, new emotional associations. This opens exciting possibilities to develop new neural pathways (for skills/understanding/meaning) and the resultant brain plasticity literally rewires the brain – so valuable for this population. It’s never too late to learn.

Views on ‘meaningful time’, meaningful experiences

Feedback from all stakeholder groups appeared to refer to the significance and appropriateness of this Frozen Light theatre experience. One of the challenges of analysing this data was the clear fact that responses from all involved parties was unanimously positive, so there was little to balance this perspective. Even respondents who added suggestions for potential improvements (*an incredibly small number*) prefaced their comments with affirmative or complimentary views. One question then ‘is this because there is little to improve on?’ ...or, is the issue more about the limited availability of dedicated and appropriate theatre experiences for people with PMLD?

The views of the audience members (companions) were interpreted to relate to perceptions of the engagement and meaningful experiences of the people with PMLD – perhaps speaking as proxy for those individuals themselves.

- Q *Absolutely amazing show, our pupils [with PMLD] were so focused, engaged, quite emotional to see. Would really love to access more theatre like this. There is a definite gap in the market & companies like you can really make a difference - so well done!!*
- Q *Both of us really enjoyed - v appropriate as we used to go sailing and Elliot is about to move to her new supported home*
- Q *Lovely sensory experience, Kirsty really enjoyed. She loved the mixture of sounds, touch & smells*
- Q *Amazing! So engaging - even for adults! [companions]*
- Q *Performers read the clients body language and reactions to each stimuli and acted on this. Wide variety of stimuli used to grasp + maintain attention.*
- Q *Relaxed atmosphere so felt comfortable supporting someone who enjoys been up and moving about. Thank-you :)*
- Q *beautifully thought out and delivered performance... to see our service users react so positively was amazing to see*
- Q *I am lost for words in total awe of the immersive, personalised experience. It’s left me so moved. Thank you for this lifetime memory.*
- Q *brilliant for the person I was with who was visually impaired and loved the lights and music*
- Q *excellent display ...with so many sensory enhancements. Thank you for providing the opportunity to experience a new & exciting show, adapted to these special guys*
- Q *Amazing performance. Age appropriate. Thoughtful and engaging...*

As the individuals with PMLD were unknown to them, the views of expert reviewers took on a more expansive interpretation;

‘[the show] pushed the boundaries of a relaxed performance ... pace and pitch couldn’t be more perfect – so clever, all the continual elements to engage the audience – singing to each member – playing with pebbles - the light box, vibrating radio, hot water bottle, biscuits. The audience were part of the performance.

‘A master class in performance for individuals with PMLD... They clearly know their audience very well –[a] well researched, developed and constructed piece of theatre.

‘Quality of performances was exceptional both from execution to attention to detail [to] audience engagement’

‘... audience were all mutually engaged and careful to include all in the performance although it was about the individual with PMLD.’

(CEO of a city theatre trust)

‘Six audience members were gently transported into the story and the space between the stage and spectator disappeared...’

‘It gave me real hope and a vision for how people can experience their world (our world) ...The story was literally brought to people.



‘Supporters and carers scrambled to take photos and capture expression and delight. This, at first, threatened to overpower the performance but I quickly realised that the motivation to do this came from the right place; an excitement to see people take part and an urge to ‘show’ others what it was like.’

(Head of Involvement and Engagement, LD Social Care Provider)

‘The Isle of Brimsker was quite simply the most inspiring example of how to engage with and entertain people with PMLD that absolutely values them ... we can all learn ...to help make their world more interesting, participative, stimulating and real.’

(Health & Wellbeing programme Manager, LD Social Care Provider)

‘I sat watching in amazement, as each performer engaged on an individual level with their audience. Their facial expressions echoed their audience members, like a mirror reflecting wonder, joy, amusement. Everything about this production was #amazing, thanks @frozentheatre.’

(Day and Residential LD Service provider)

One expert reviewer focused her remarks around the techniques employed by Frozen Light and more specifically, their use of sensory props to give meaning to the dramatic changes and storyline in an accessible format.

‘The movement of the actors across the stage - and on various levels...the use of music, both helped them [people with PMLD] attend. The level of engagement was phenomenal.’

‘As sensory beings they need sensory resources to provide information – this is how we learn. The sensory information

in this case tells us about the story and our sensory feedback guides our responses... Scented stones, tactile shells, contrasts of hot and cold, vibro-tactile pool and rope, hot water bottles, illuminated balloons and a shimmering glitter curtain which entertained them throughout – looking, stroking, batting [it].’

‘Frozen Light are providing the multi-sensory experience our sensory beings need. Not only that, they are providing experience, empathy, understanding and a very specialist service.’

(Multisensory Activities Specialist)

Previous discussions have highlighted the importance of structure as a means of supporting the understanding of people with PMLD, and this approach is certainly one that provides strong evidence of practice that ensures ‘meaningful time’ for each audience member. This performance has an underlying structure that offers some cues to starts and endings within the overall storyline; this allows the story to unfold in shorter chunks of multisensory action and experience. Poor working memory, distractibility and a short attention span are characteristics of this population, and so shorter schemes book-ended with pauses for reflection can be easier for the person with PMLD to attend to (also creating cues that something different is happening next); the use of such structure facilitates anticipation and greater engagement. The value of pauses is vital with individuals with PMLD; they provide a space or void in which to reflect, giving time to process information – about each sensation or experience (particularly when it disappears/ends) and what will happen next.



The Isle of Brimsker draws on short, repeated sequences of music, narrative, 1:1 interaction and taking turns to engage with sensory props. These sequences were punctuated by the use of the shipping forecast as a cue to change. A vibrating radio, with rainbow LED lights quickly moving across its screen, dramatically broadcasted a change in the weather ... and the start of the next piece of narrative.

Frozen Light team members commented on revisions and improvements they made as the tour progressed; these were responsive actions to their ongoing monitoring of the show's impact, to ensure it was meaningful to the audience of people with PMLD.

- Q *'[as a team] we reflect on every show - sometimes it's very lengthy ... [we make] tweaks - changed the choreography to improve the creativity and keep their attention. We often have to return to the scripts, especially as it's so easy to over-run when people are very engaged in sensory moments. There's a real tension there - the challenges of keeping a show and those 1 to 1 moments - you know how beneficial those are - and for their wellbeing.'*
- Q *'One of the best bits - knowing [we] reach out to people who don't experience that normally. Their reactions are beyond expectations - even from those who know them'*
- Q *'You judge things- from gut feelings - the whole ambience. Some shows you really feel the energy and see from the others [performers] if it's going OK or a challenge - from the audience [with PMLD] or a challenge from their support workers. You see positive reactions, real engagement -and when it's encouraged -or not.'*
- Q *'At a macro level, the sensory aspects are key...lines of dialogue may not reach them, but they are involved and engaged in the sensory artefacts - taken directly to them - so important to how they perceive [meaning].'*

- Q *'One of the big challenges - not always possible to stay in the 1 to 1 with that person- time to 'get through' to unfamiliar people with PMLD - but at least that [aspect] has more flexibility than the creativity perspective.'*
- Q *'Our guts are always in tune with the audience [people with PMLD] and in tune as a team, to follow their lead. BUT - don't always succeed with everyone - important to, learn from and include sensory beings!'*
- Q *'Best bits? The complete joy you bring to someone's life.'*
- Q *The Isle of Brimsker was underpinned by well-researched development and design. The way this show was executed with meticulous attention to detail by Frozen Light, pushes at the boundaries; it challenges the established principles of good practice in supporting [us to] recognise falling short is not a failure - it just may not be the right toolbox today ... sometimes [we] failed to communicate and engage with audiences, but now... [we have] a whole new tool box and energy to listen to and enable people with PMLD.'*

Raising expectations

Experience tells us these individuals have the greatest understanding and control over their lives when life is consistent and predictable, when they are supported by people they are familiar with, who know them well and can interpret their personal communication style. Yet, here we see the complete contrast. Individuals with PMLD come to an unfamiliar location (theatre) into an unusual environment (dark auditorium) in which a constant sequence of dramatic and special effects appear to randomly occur - and then, they are faced up close and personal, with people they've never met who expect to interact with them. But it works - and with great success. This must be the ultimate test of adaptive behaviour, of generalising skills to an entirely novel context.

Standard 6 Transitions & Change

Extract...

Change and transitions are an inevitable part of normal life. Some of these transitions are predictable and can be well-planned in advance ... other[s] may be unexpected however, they also require a sensitive personalised and timely response. ...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.

PMLD Standards for Individuals - Standard 6: Transitions & Change (p34-35)

Change is an unavoidable aspect of life; it happens to everyone. The ability to cope with that change differs from one person to the next, and people with PMLD are no different. Similarly, they too will encounter many, many changes through the course of their lifetime; some minor, day to day shifts, whilst other change may be significant and transformative transitions. However, what does differ for this group is their aptitude to manage and cope with change, without compromising their whole wellbeing.

Some changes may seem very small in nature to us, but for people with PMLD, even tiny differences may cause distress if not handled very sensitively. It is probable their necessary resilience has not developed, their ability to adapt to change or to bounce back emotionally from feelings of loss produced by that change. Accruing positive experiences are crucial to developing the skills and resilience for improved success in expressing themselves and coping with change.

People with PMLD are often considered to 'live in the moment'. Their profound intellectual impairment impacts on their understanding of the world, their working memory and their ability to generalise skills and understanding in order to adjust to new

situations. Learning for everyone is dependent on consistency and repeated experiences to lay down neural pathways until knowledge, skills and understanding are established. In people with PMLD, these opportunities for consistency and crucial repetitions in their lives are more limited; those neural connections therefore may be absent or not yet fully formed. This factor, together with poor memory recall, may mean each situation for some individuals is experienced as if it was the first time. As a result, it is possible that some individuals live in a state of heightened anxiety (fight or flight) - unable to predict what might happen next and with little control when it occurs.

After the show, Connor's parents told me about their very different experience at another theatre - one that had not ended well. They booked a musical for the three of them - months in advance. Their tickets confirmed a wheelchair space for Connor with a seat either side for them - to support him in this unfamiliar venue. When they arrived, the theatre had forgotten to remove seats from the auditorium to create Connor's wheelchair space. Their only alternative was for Connor to sit in the aisle, quite a distance away from his parents seated at the end of a row. Connor has limited movement so couldn't easily turn to see or reach for the physical reassurance he needed in this unfamiliar place. Without this comforting his anxieties grew. This triggered an epileptic seizure, bringing an unnecessary and disappointing end to their theatre visit.

Getting things right for people with PMLD includes thorough preparation (where possible), opportunities to become familiar at their pace with small, manageable steps of change (again where possible) together with active support that reassures and empowers them holistically (i.e. sensitive and responsive to their emotional, physical and social wellbeing).

Four years ago, one man with profound disabilities (then in his early 50's), made his first ever visit to a theatre. He loved the elements of Frozen Light's multisensory show - it seemed totally appropriate and accessible for him. But because everything was so new - the venue, being in the dark, experiencing live music and theatre were all so unfamiliar - he became increasingly anxious. Being so stimulated, he was unable to regulate the sensory information - he was overwhelmed and distressed and had to leave the theatre. Everyone was disappointed for him.

When Frozen Light announced their next tour, the man's sister contacted them asking for some early insight about the new show to help him prepare. An outline of the story, list of props and a copy of key music tracks were willingly shared. The man was supported to learn about these new experiences over the next few months, in familiar surroundings and supported by people he knew. Before the show, he made several visits to the theatre, having a drink in the café and even sitting in the empty auditorium. His second visit to a Frozen Light show, although still a challenge, was more successful as a result.

Prior to The Isle of Brimsker tour, a similar approach was used. This time the man's multisensory activity specialist saw the show first, enabling her to identify potentially challenging elements of the show. Weekly sessions helped to familiarise him with the auditory aspects (a real challenge to him) and to become more confident touching and physically engaging with

the sensory props (also a challenge). On this 2019 tour, he saw the show twice – the first time in the familiar theatre venue; the second show was several weeks later in a new theatre. Although a little overwhelmed towards the end, he not only managed to cope with the whole performance on both occasions, but was intensely engaged for the duration, watching the performers wherever they were on stage and even smiled when they sang his name.

Frozen Light's previous tour experiences highlighted that their target audience of people with PMLD were a group frequently exposed to major transitions. Many of its audiences comprised young adults on the precipice of making life-changing moves from home to supported living or more generally, from education and children's services into adult services. A transition from a very familiar context (home or school) surrounded by people who have known them for all or most of their life until, at the age of 19, they transfer to the completely unknown territory of adult social care - an enormous loss and challenge simultaneously. Other, often older, audience members were also experiencing the challenge of loss and change; austerity cuts to social care often meant a frequent turnover of their carer and support teams, of people losing their long-term day services and the associated social networks or, having to move to alternative (cheaper) accommodation - often with little or no say, relocated to completely new areas.

Q [The Isle of Brimsker themes were] very appropriate as we used to go sailing ... and ... Elliot is about to move to her new supported home.

Friendship, isolation and how we react to change

The Isle of Brimsker aims to 'create a safe space' for their audiences, in which to explore the very relevant central themes of 'friendship, isolation and how we react to change' facilitated by the three characters Kaya, Agata and Igor.

In this performance, Frozen Light create layers of theatrical experiences as a well-researched, well-designed technique. They build these layers from evocative music, emotions and dramatic narratives along with other physical and sensory experiences. This layering technique offers a variety of levels of access, enabling the audience members to personally engage with the performance in the most appropriate ways for them, particularly when addressing these more challenging issues.

As a reviewer, I was able to experience the effective use of this layering personally and through the first-hand observations of audiences at ten performances.

I myself experienced and I witnessed others' experiences to the unfamiliar environment and its unusual features, to the changing cycles of time, weather and contrasting locations, in response to the unexpected sensory sensations, – but especially too, the raw, deep and heart-felt expressions of mood and intense feeling created by this storyline.

It was emotionally powerful to see the sensitive connecting of audience and performers, previously unknown to each other ...

and the remarkable responses (however tiny or subtle) captivated in the moment from their focused attention to the sensory wonders they were feeling for the first time or, transfixed simply by that human connection.

Just as evident was the visible intensity of the audience's concentration; their noticeable responses to the clearly unexpected, changing relationships and the sheer raw emotions of the show's two main characters, likely unfamiliar to many. Every feeling and response felt salient, tangible and meaningful to them, to the performers – and to me as observer.

The use of multiple layering offered encouraging gestures to the audience - invitations to experience small increments of change, reassurance to venture into the unknown or even, to step over the threshold (literally, in parts) towards more demanding transitions. Companions as well as the people with PMLD were observed looked slightly unsure as they entered the frequently unfamiliar theatre venues; they appeared uncertain what to expect from the performance and looked anxious about what they might 'have to do' They were taken aback to see the show began in the waiting area. Kaya came out to greet the assembled group and took individuals one at a time into the auditorium, to their seat and personal shelter. Carers were confused, even a little unsettled at this unusual style, but Igor's serenade calmed their emotions and paved the way for the story to unfold.

Feedback across the range of stakeholders commented frequently on how people were made to feel safe, secure, comforted whilst exploring unexpected and often alien occurrences.

'Before the performance we could familiarise ourselves with the characters and what to expect with a visual story. [sent out with tickets by each venue]. This helps remove the fear of unpredictability. Then, to the accompaniment of gentle live music, we went in one at a time [into auditorium]. This aided the transition enormously, reducing sensory overload. Everyone was greeted individually, taken in at their pace and seated. This enabled [them] to feel safe and the atmosphere to be calm.'

(Multisensory Activities Specialist)

'What are the signs of a good show?... 5 star reviews? A recommendation from an old friend? Big production? Big Audience? Perhaps some of all of those things help us build a picture, but the real sign for me is one I felt (yes, not read or heard...felt) during and after 'The Isle of Brimsker' by Frozen Light Theatre. I felt connected, immersed, and somehow, full.

'Was this a 'show'? It felt (there's that word again) more like an experience; something that was more than just in-front of me but captured me and other audience members in a wonderful dream, enhanced by a realisation that this is a moment in time that my memory bank will cherish and keep safe.

'Five minutes after it had ended, I was sat in my car motionless with an invisible bubble over my head reading "what just happened?". I loved it!

Truth is though, it wasn't for me. I mean the company and performers had made me feel like it was (they're very lovely and talented folk) but it wasn't. Six people lined up in the front

(and only) row and were instantly immersed in this experience; an almost fairy-tale story of what comes of our thoughts when left alone and how the world changes when we experience things together. It was fitting as the six audience members were gently guided into the story and the space between stage and spectator disappeared and we all became one.'

(Head of Involvement & Engagement, LD Social Care Provider)

Anticipating change

Changes throughout the show were subtly cued, alerting the audience to anticipate something different was following, one after another. Changing the mood was often created with music, song and silent pauses, coupled with acting to give a visual portrayal. Ebbing music created a lull for Kaya and Agata to each share their stories, their matching echoes of isolation. The strengthening waves were getting louder and the radio's shipping forecast signalled the brewing storm. The sensory feel of the water spray and wind machine on our faces set the scene, matched by the up-tempo soundscape and speeded up choreography – they paved the way for heated exchanges between Kaya and Agata – each aspect added to the escalating fear and drama of the changing situation on Brimsker. Audience members were clearly on board, through every performance – eyes widened, mouths open, the arm of their neighbour tightly grasped.

We next see the characters home and dry within the safety of the lighthouse. This was yet another transition, one moment in darkness battling the elements of nature, the next moment in the now warm light and calm haven of home, where the hiatus of emotions was now laid bare. The simple acts of kindness Agata offered to Kaya (the hot tea, the biscuit, the hot water bottle) were an unexpected catalyst to dislodge her emotions and she broke down, sobbing. Some of the audience stilled in silence to witness this, others actively sought out reassurance with their glances, gestures, facial expressions.

The narrative moves on with hope, compassion, friendship and togetherness, sharing in the awe and wonder of the rising moon, the beautiful Northern Lights. A shared finale sang out in three-part harmony to express the promise of happier times.

The Frozen Light team reflected on their approach to support their audience members through experiences of change offered by *The Isle of Brimsker* UK tour:

Q [this is a] ...huge leap from previous shows and what we did. Sometimes we're at the limits of what we do now – capacity-wise. Any [more] change we lose the intimacy, that hands-on that helps them through

Q Limitations? Lots of opportunities [for theatre] in schools and younger children – but huge gap for adults - and teens – when they probably need it most

Q The audience experience – needs to be the best it can be. Always hard to gauge understanding, their 'insider view'. Music ...makes it accessible ...every show music and singing 'got through'

Q Key messages? Recognition and respect – their needs, respecting their abilities ... without funding [for this theatre] we will never know their strengths. Respect as a human beings. We cannot expect to change their life but [we can] change the people around them.

Q Cannot assume audience understands. Understanding and appreciation are different. [we] create an 'entire world' – [we] use a black box and rituals of performance, trickery... music and lights work together, one can spotlight the other ... sounds add meaning – the cup of tea and a 'bing-bing-bing-ing on the piano catches your attention to get a biscuit. Soundtracks create ambience, what glues it together.

Q There's a continual process of intertwining – music with narrative and technical stuff to create a homogenous performance – that creates the emotional level of a scene, the back story ...and the characters. They can access different levels depending on capacity – or just want to sit back and watch

Q Don't want to wrap [audience] in cotton wool at the expense of the experience – no need to err on the side of caution ... [so] it envelops you – a real joy and experience itself.

The Frozen Light Team also made reference to witnessing the influence of change on the wider Isle of Brimsker audience – for carers and companions but also for theatre staff too.

Q Talking about the theatre staff awareness of people with PMLD, '- its new to them too'. [At a new venue where they performed six shows over three days,] 'you see people change ... relax and grow into it – all of them, front of house, technicians, the lot. The whole theatre is part of this experience – more than "just the next show"

Q One Mum who knew us [Frozen Light], her son died just three weeks before this show date ... she gave her son's ticket to someone else. She still came to the show though – she said [of the show] "it's vital. Not just that it's great theatre, it's all just for them"

Q It's pretty much new territory for the whole audience. One guy, a carer 'with a pretty hard exterior'- told me this really wasn't his thing – saw him later after the show – gave me a fist pump -and I thought "bank it". [It's] all about people - whoever you reach

The audience were actively carried through a roller coaster of emotional and sensorial change but protected within the sequences and shelter of this performance itself. The multisensory experiences were stark contrasts and extremes; for example, a slammed door then immediate peace.

Lights up ... we shared in joy-filled smiles and laughter, out of our seats and wheelchair spaces to make collective, physical contact ... we made it through, together. It was truly up close and personal (indeed, brought to the audience) and under the spotlight, literally - difficult to miss – but that was the point.

5c PMLD Standards for Organisations: introduction to findings relating to organisations and providers

The focus of this evaluation remains firmly centred around adults with profound and multiple learning disabilities (PMLD) and the potential and evident benefits to them, from their participation in *The Isle of Brimsker*. However, the review will also be considered within the context of a wider picture, to encompass the whole Frozen Light-local community-theatre-experience.

In this next section, the discussion that follows explores a number of broader but relevant issues that had bearing on the overall outcomes from *The Isle of Brimsker* experience for the target audiences of adults with PMLD. Many issues directly or indirectly played a part on the degree of success and enjoyment of this one-time event. Such issues may have contributed positively, but others created barriers. Some were issues that were unexpected, unplanned and beyond the control of all those involved in this theatre visit, whereas others were completely within the realms of being addressed - improved, overcome or prevented.

A general review of these issues identified will be briefly considered against the set of Standards for Organisations. This set of standards offer a quality assurance framework that sets out benchmarks for every organisation providing any type of service to people with PMLD, in any setting or context. These indicators clarify the actions needed by organisations in order to meet the holistic needs and outcomes for people with PMLD as detailed in the quality indicators of Standards for Individuals.

For this review, evidence and observations will be drawn from more than one perspective - the core actions and practice of the Frozen Light company, those of the theatre venues involved in *The Isle of Brimsker* tour and in parts, those providing the direct care and support for the individuals with profound and multiple learning disabilities who attended this show. Although each of the PMLD Standards for Organisations will be considered here, some standards have greater or lesser relevance for these provider groups.



Standard 1: Leadership

Extract...

...promoting a culture of strong values ... accountability, risk taking, creativity and ...reflective practice

Respond to the holistic vulnerability of people with PMLD...

Demonstrate inclusivity or people with PMLD in... organisational practices and provisions

PMLD Standards for Organisations - Standard 1: Leadership (p20)

Frozen Light – leading the way

The entire ethos of the Frozen Light company maintains people with profound and multiple learning disabilities at its heart. Strong values and respect for these individuals as the unique people they are and the contributions they make are embedded at every level of their practice.

This review identified a wealth of supporting evidence for this standard. Some examples include:

- Values: the complex needs of individuals with PMLD are considered across the whole theatre experience, from the point at which a person calls a prepared and informed venue to enquire about the show, to informative pre-show resources posted out to the individual with their tickets, the personal warm welcome, the individual guidance into the auditorium and nurturing introduction to the performance itself-through to the performers physically interacting with each audience member post-show.
- Risk-taking: Frozen Light push at the boundaries of risk-taking. They create opportunities for this population to explore and respond to some often unfamiliar and challenging contexts, within the deliberately-created safety and parameters of their theatre experience.

- Creativity: this company are masters at creativity; however, they actively seek out comment and guidance from experts in each field to ensure their work is the best it can be.
- Including people with PMLD in organisational practices: Frozen Light build in piloting performances with people with PMLD and their familiar carers as evaluators. They talk extensively of the value of this role within their research and development phase and the often radical changes they make as a consequence of gaining deeper insights into the preferences, interests and access needs of their audience.
- Accountability: gaining feedback and advice on their work is an embedded and valued element of this company's practice. This review found evidence of actions to improve the ease of participation in the review process (offering a range of user-friendly options for audience feedback) and independent review.
- Reflecting on practice: the Frozen Light team members each highlighted the importance of review and de-briefing after every show and each venue visited. Changes and developments were observed by the reviewer between the ten shows visited over the final six months of this tour; for example, adapting the format to accommodate the available/limited space at different venues, and displaying signage suggesting the use of video/photography be limited to ensure the audience members were not distracted by this potentially intrusive activity.

Areas to develop further:

- » Frozen Light continue to explore the concept of people with PMLD themselves giving direct feedback on each performance. They acknowledge the need for this to be immediate, 'in the moment' and available to their diverse audience by any means.

Theatre venues

This review found evidence across the full spectrum of quality and values against these standards.

Venues that uphold this standard (as measures of the value they attribute to audiences of people with PMLD) demonstrated their position in a number of ways. This review found evidence to map to certain aspects of the standard, including:

- Culture of strong values, accountability, risk taking: Some venues showed an explicit commitment to recognising this population as valued audience members through their programming, using creative approaches to offset the greater costs, and working hard to reach the target audiences. Examples noted included – repeat bookings of companies such as FL or, offering multiple dates for *The Isle of Brimsker* including evening or weekend shows to enable families to come together and a commitment to offering 'appropriate events' in each season's

- programme.
- » people arriving at the theatre were not made to feel welcome or valued
 - » information was frequently confusing (frequently inaccurate or non-existent) – about the show, where it would take place, where to wait, what to expect
 - » in at least one venue, this adult show was marketed as relevant for the very young or pre-school children
 - » waiting areas and public amenities were not always appropriate or fully accessible to this audience
 - » accessible and meaningful theatre was scarce - in opportunity, frequency or locally – audience members reported;
 - she's only been to the theatre 3 times in their life (aged mid-40's) seeing every FL show - because there was nothing else for adults with PMLD
 - numerous accounts of people travelling for 'an hour', 'an hour and a half', 'over two hours', 'making a day of it' ... because this was a rarity and there were no shows locally ... or to see it a second time.
 - » attitudes of some of the theatre staff observed demonstrated stigma and discrimination towards people with PMLD and their carers. The prejudice was sometimes unintentional (uninformed), but other behaviours possibly intentional or entrenched (and completely rude/disrespectful).
 - » few managers, programmers or senior theatre staff took up option to sit-in on a performance across the venues. When the reviewer enquired if they had seen the show, many said they had rejected the opportunity. On one occasion, another member of staff offered to take on the 'on-call' role to enable this, but the manager declined; another said he would watch from the gallery behind- missing the impact of the show/s audience interaction and the visibly telling expressions from those key people.
- Some venues went to great lengths to welcome this audience, most of whom were not familiar theatre attendees. Findings noted – warm, meet and greets by front of house staff, reassuring explanations of the FL approach to this very relaxed, very inclusive performance; a dedicated, quiet and spacious waiting area- also offered as a break-out space for anyone needing time out from the show; relaxed, informal chatting with the audience to gain insights and feedback both pre and post-show
 - Theatre staff in some venues were very eager to sit-in on the performance to understand this audience and their needs- some theatre personnel were very engaged and interactive with audience members during the show. Post-show these staff members expressed this experience to be of immense value e.g. making them think more about 'relaxed performances', understanding some of the very basic needs of this group – to access the café area or for personal care. One person specifically mentioned that they made special amenities available in their theatre for young children to have a play area- and realised they could so easily create a quiet zone for people who may need a calm and less stimulating environment

Areas to develop further:

The audiences of people with PMLD are, understandably, not familiar to theatre venues or their personnel – including volunteer staff at many venues. Although awareness and accessibility training should be integral to every venue, their staff induction is highly unlikely to include any real understanding of the additional needs and access issues of this specific group. As a proactive response to this fact, Frozen Light offer written guidance and face-to-face briefings for every venue, for personnel involved at every level of the theatre experience. This includes constructive advice and often direct action to support programmers, promoters and those involved in every aspect of developing an audience base and ticket sales.

- » A large number of venues do not take up this valuable opportunity for awareness sharing. There were a whole host of reasons; for some, it was a deliberate choice (not disclosed or e.g. already have expertise in inclusion/relaxed performances), for others, their response is a default position (e.g. not having enough staff to cover to allow it to occur, staff not being advised this was available, or just not turning up to planned briefing).

As a consequence of not following the advice from Frozen Light, the outcomes and experiences of the audience were influenced, often negatively:

Standard 2: Quality

Extract...

Ensure an effective quality assurance and improvement strategy using quality and auditing tools that create a learning environment for all staff

PMLD Standards for Organisations - Standard 2: Quality (p21)

Frozen Light

Many examples of evidence supported this standard, including for example:

- This theatre company has a board of trustees whom they report to. This group require rigorous quality assurance measures from the Directors.
- Quality measures were seen to be embedded in a wide range of documentation shared by Frozen Light.
- At the practice level, the direct impact of their work is under constant review by the two Artistic Directors, the performers and others in the Frozen Light Team. Informal feedback is gained from each venue, some venues sharing their own internal reviews with the company.
- Audience feedback is key to their day to day review, considered alongside the internal lens of the Frozen Light Team post-show reflections.
- This independent review was commissioned.

Frozen Light were keen to gain feedback and comment from an Arts perspective:

- Published peer reviews and interviews were gathered, scrutinising them for insights that could lead to further improvements to their work and expertise.

From the perspective of learning and improving, one major concern regarding the ratings of audience members was that they were so positive, almost without a single exception. Of those who rated below 9 out of 10, a handful left no additional views, while others added comments of:

- Q [rated 6] *Amazing. Fantastic. Superb. It was wonderful to see how engaged all the pupils were. Thank you.*
- Q [rated 8] *Really enjoyed it. A novel approach with wider perspective on communication and meaning*
- Q [rated 8] *Fab!*
- Q [rated 8] *Woke up especially to watch*
- Q [rated 8] *Lights were a bit bright at times - but no seizures thankfully!*

Areas to develop further:

- » Check database for greater accuracy of audience feedback.
- » A further review of approaches to post-show audience feedback would be worthwhile to address some of the challenges and issues identified through this review. Offering feedback cards before the show could be considered. This would inform people what they would be asked to reflect on and could enable basic information to be completed before the show.
- » Frozen Light continue to explore the concept of people with PMLD themselves giving direct feedback on each performance. The simple use of 'pauses' (or not so simple) as spaces and time for processing and reflection, could be explored both within a show and at the end of a show. Most of society has the cognitive capacity to switch almost instantaneously from one stimulation to the next; people with PMLD need a far longer processing time – usually longer than you think (or feel it should be). It is very easy to 'jump into that space' thinking a person may not respond, but if we wait a fraction longer, whilst they assimilate that experience or notice that it ended...what was it...? did I enjoy it...? would I like more...? or, what's next?
- » Complete an audit or checklist on each venue relating to their awareness and action against Frozen Light directions and offers of support – e.g. take up of staff briefings, sending out pre-show information with tickets, preparations to respond to additional needs (such as personal care requirements) and technical preparations for the show itself.
- » Request a written review from each venue offering their feedback on the experience and raising issues and challenges from the venue's perspective.

Theatre venues

This was not an area directly investigated by this review. However, of note to this standard on quality assurance, some relevant observations were made of positive actions:

- Many theatre staff were seen to be eager to sit-in on *The Isle of Brimsker* – this included staff from varying roles- box office, café, front-of-



house, technicians, and some individuals even came while they were off-duty.

- Informal, post-show conversations highlighted the perceived benefits from this, as one person coined it, 'immersion experience'.
- Comments suggested these observations enabled them to better judge the 'success' and 'relevance' of the performance to people with PMLD.
- Theatre personnel commented on the accessibility of their individual venues- and the shortcomings.
- A number of people commented that it challenged their concepts of 'relaxed performances' and 'real inclusion'.

However, the reviewer also witnessed less than positive practice where the venue was not prepared or informed:

At one venue, an apparently uninformed/inexperienced and visibly very nervous front of house staff member was observed sitting-in on the show, at the back, taking notes. After the show, she asked several members of the Frozen Light Team if the show was a success. She had been tasked with writing an internal report on the show, reviewing its value/benefits but had no concept of what this might look like or why. She was seen observing the performance from the back but paid little (or no) attention to the responses of the audience members with PMLD.

Of particular note were that the two particular shows supported by this member of theatre staff were perhaps acknowledged as the 'least successful' shows of the tour - due to a raft of uninformed, unprepared and poor-quality actions taken by that venue:

- » Mis-selling of tickets and a no-show meant the first show of the day had only one adult with PMLD in the audience; the second performance had two adults with PMLD. There was evidence of other people with PMLD having been refused tickets unnecessarily.
- » Complete confusion by venue staff led to the audience members hanging around for an overly lengthy wait in an extremely busy reception area (whilst theatre staff explored the issue of mis-sold tickets).
- » The noisy reception area was visibly inappropriate and uncomfortable for the adults with PMLD – and their carers; each individual with PMLD was visibly overcome and even distressed entering the show.
- » The theatre experience for the adults with PMLD was detrimentally affected by this poor quality, pre-show experience and for companions too.
- » This venue had not enabled the duty staff to be able to attend the pre-show briefing.
- » Technicians at this venue had not adhered to the directions of Frozen Light, meaning many essential technical elements of the performance were not prepared as requested.

Standard 3: Staff development (skills and confidence)

Extract...

Provide well-trained and supported staff, deployed in the right places at the right times

Evidence of values-based recruitment

PMLD Standards for Organisations - Standard 3: Staff development (p22)

Children's Services, and their personnel have greater access to continuing professional development than those working within health and adult social care settings and services. In many situations the skills, understanding and direct practice of care workers may be 10, 20 or even 30 years behind what we now consider to be 'good practice', and hence the need for the PMLD Standards to improve this position.

Insights and understanding about the holistic needs of people with PMLD – the fundamentals of their intellectual disability, impairments and other commonly experienced barriers like sensory processing difficulties - may never have been shared with staff. Training therefore, in enabling the interaction and 'voice' of people with communication difficulties or supporting the sensory and engagement needs of people with additional impairments, is even less probable. Important and appropriate approaches such as Intensive Interaction, Sensology and sensory regulation/ integration are likely to be unknown; positive engagement techniques including on-body signing, hand-under-hand support or cueing are also quite feasibly unfamiliar. A caveat is needed here, that (generally speaking) staff in specialist education settings (schools and colleges) are more likely to have had at least a basic induction in these areas and frequently more advanced professional development; for some, this knowledge and skills will be embedded in their everyday practice.

Frozen Light

As a theatre company, Frozen Light have well-documented evidence of keeping up to date, skilled and informed by experts. Their research and development process models this practice as does their activity outside of their own performance-working. Such evidence includes:

- new members to the Frozen Light team are taken through a thorough induction including familiarisation with the PMLD standards, followed by ongoing in-situ mentoring in practice
- Frozen Light co-facilitated a national seminar for Arts peers working within the area of theatre/arts for people with complex support needs
- Frozen Light presented their work for audiences with PMLD alongside their arts peers as part of this seminar
- members of the Frozen Light team undertook a two-day master class on sensory engagement, sharing their own insights on that programme

On one occasion, an invited reviewer suggested Frozen Light might consider further exploration of the Intensive Interaction approach to be beneficial in response to their observation:

Q *We saw ... two audience members [with PMLD] offering sounds and movement in their individual responses and these were golden opportunities for the performers to look out for and interpret any*

Every provider of services to people with additional needs should endeavour and are legally required to ensure their workforce are aware and sufficiently informed to understand issues of diversity, equality and access. If the widening participation agenda across the Arts is to have any success, theatres and other community services must create a strong values-based ethos and culture that promotes a genuine sense of inclusion. This needs to be enacted beyond mandate and policy documents; it should be demonstrated through their personnel and their activity (in the broadest sense).

Of relevance to this discussion is the role of care and support providers. In the main, paid companions supported the adults with PMLD to *The Isle of Brimsker*; a significantly smaller number of this audience were accompanied by family and friends or sometimes volunteers.

The education, health and social care workforce are required by law to train their employees to at least basic levels to safeguard the people they are supporting and to meet the health and safety standards set out in legislation. The reality is personnel (paid carers and supporters) will have been trained in mandated areas such as manual handling, fire safety, basic first aid, fridge temperatures, cleaning food preparation surfaces as part of infection control and safeguarding. There is a high probability that very few will have received even rudimentary training about how best to support individuals with PMLD to interact and engage with the world.

However, there is a huge inconsistency between these public sectors in opportunity for workforces. Education comes under the jurisdiction and funding of

intentional communication ...the gentleman was vocalising ...the lady was rocking to the music. We would have liked to have seen the performers pick up on these aspects...use these moments to get to know their audience...'

Theatre venues

Frozen Light present each venue the opportunity for face to face staff training, information, guidance and direct support (as a form of mentoring). These actions have the potential to raise awareness and support personnel at every level and in every role around meeting the needs and enabling access and engagement of this population of people with PMLD:

- Informal conversations with venue staff illustrate the value placed on the Frozen Light induction to people with PMLD.
- Theatre box office staff felt more confident to describe the appropriateness of *The Isle of Brimsker* and the target audience following the support and guidance from Frozen Light.
- Some staff were confident to seek and reach out to new groups in order to develop their audience base of adults with PMLD.
- Individuals commented on feeling more able to interact with people with PMLD before and after shows having seen the role models of Frozen Light.

However, take-up of the proffered support was not widespread. Not all venues valued the opportunity for staff development or to widen their understanding of marginalised groups:

- » In a number of venues there was a lack of awareness and clear misunderstandings about the target audience, which led to inaccurate programming and mis-selling of tickets.
- » Some venue staff were unaware of human rights and equalities legislation, leading to some prejudice and discriminatory remarks.

A Frozen Light team member reflection highlighted:

Q 'Longer runs at a venue [are] really valuable, you have greater influence on staff, attitudes, the venue itself'. Further comments suggested, as time progressed, they saw venue staff visibly relax as they became more familiar, and then saw the benefits of this type of theatre – until they too started to enjoy the interaction happening in front of them.'

Supporting adults with PMLD

The work of Frozen Light through their performance is akin to a living 'role model'. Their actions speak their ethos; they 'walk their talk' in every element of their work, the design and planning, the pilot phase, and optimally, each show they perform. Every performance observed upheld the same quality and



degree of expertise, respecting each adult with PMLD (and other audience members) as if they were the most valued person alive (even two shows at one venue which would have challenged anyone, with even a lifetime of experience and skill).

Although the performers actively look to the audience member's companions for advice, for clarification of the best way to interact and gain engagement with individuals with PMLD, it is apparent even to the inexperienced that Frozen Light are masters of this craft. Through their approaches and performance, they demonstrate how to 'do' respect, creativity, compassion - valuing the person for who they are and what they do; however subtle that response, it is 'heard', recognised as important and responded to with admiration. They offer so much to those involved in improving the lives of people with PMLD.

The reviewer observed the whole range of skills being used by companions to enable people with PMLD to engage through *The Isle of Brimsker* performance.

Supporters were seen using a variety of positive support and enabling strategies. Some themselves demonstrated what to do as a form of encouragement and reassurance to the person with PMLD, to try something new; others gently offered physical prompting to initiate a person's activity, whilst still others varied the position of a sensory item to enable better access and elicit a response.

On other occasions, support was of noticeably poor quality and even non-existent – all examples suggested the paid support workers were in need of further training and professional supervision to raise their practice to a more acceptable level:

- » *One support worker positioned herself behind the woman's wheelchair, not to support her from this position but to create a barrier between herself and the performance.*
- » *On numerous occasions, the audience members with PMLD remained in their coats throughout the performance, even though the staff removed theirs immediately they were seated.*
- » *Several observations witnessed the lack of interaction between the carers and the people in their care; some instances saw a complete lack of communication, nothing verbally or non-verbally, no eye contact or even gesturing to tell the person with PMLD what was happening – just things done to them, tugged their coat to sit them down, pulled them out of their seats at the end of the performance – as if they were not human.*
- » *People with PMLD were sometimes 'parked' and left to their own devices with no support.*
- » *One carer made it obvious she did not want to be with the person she had wheeled into the theatre. Despite sitting right next to this gent, she physically turned her back to him throughout the show, giving her full attention to another man (already supported by someone else). The young man made frequent enthusiastic attempts to gain her attention, for reassurance and to share enjoyment, but she physically shrugged off his touch without turning around.*

Standard 4: Physical Environment

Extract...

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

PMLD Standards for Organisations - Standard 4: Physical Environments (p23)

Evidence of this standard being achieved will demonstrate, for example, that the person spends time in environments which are:

- Within a local community, fostering relevant networks and links within that community;
- Equipped appropriately (accessible and with hoisting/changing/showering and other mobility equipment required);
- Suitable for the person's individual needs e.g. with quiet, calm areas to meet their sensory needs and preferences (for those who find it difficult to process and regulate stimulating environments).

Frozen Light

People with PMLD experience the world in closest proximity to them and through their senses and physical actions. They appear to follow similar sequences to early learners but are subject to skill development of movement, vision and hearing. For this reason, the five developmental stages of expanding space (McLinden & McCall, 2016) are worth considering when reflecting on the findings from the Frozen Light performance:

- **'face-space'** – the world is literally centred around tactile experiences through the lips, tongue and fingers because these have most sensitivity due to their greatest number of nerve endings. Experiences are mostly internal sensations with things which come directly into their face space or make direct physical contact with their mouth.
- **'body space'** – their awareness expands across their whole body, the extent of their arm or leg length and things moving across their sight line (if they have useful vision); hearing and sounds cross over senses and sound vibrations may be 'seen' or physically felt.

- **'personal space'** – learning through all they can literally reach, touch and manipulate, using an increasing number of schemes to learn about the properties of items and differentiating what things do.
- **'social space'** – widens their horizons to the area around them, this may include the whole room. This prompts action and movement towards things, to turn to locate sounds or visually track things as they move in different directions.
- **'group space'** – when individuals start to share in activities with others

The Isle of Brimsker creates its own environment; stimulating, interesting and sensitive to the needs and interests of adults with PMLD. The Frozen Light performers greet their audience in the 'outside environment' of the theatre waiting area with a musical serenade and then warmly usher them, one by one, into this alternative world of *The Isle of Brimsker* story.

From the safety and comfort of their personal 'shelter' (personal space), the audience member with PMLD and companion are gradually introduced to the storyline bit by bit, by the performers bringing sensory artefacts into close proximity (face space and body space) for exploration. Eventually, these protective shelter curtains are pulled back (social space) enabling individuals opportunities to experience the community feel of being a 'whole audience' (group space), all in this story together.

Theatre venues

The buildings and infrastructure of the 53 venues of the UK tour were reported to be vastly diverse. Whilst all would meet minimum mandatory standards of accessibility, few venues were truly fully accessible to the adults with PMLD and their carers.

Frozen Light required a performance space and audience space on a single level. In the main, these were studio and rehearsal spaces, often tucked away beyond the main public spaces. Some spaces were cramped and where the audience had come in large wheelchairs, fitting in was a challenge.

Public spaces and amenities were the main challenge. Many venues had waiting spaces away from the busy main thoroughfares of the theatre, others did not. The latter were definitely observed to be detrimental to the wellbeing of visitors with PMLD, and the poorer experiences and outcomes have been reported previously. Venues who had made accommodations to the needs of this group designated areas and even dedicated quiet places for carers to sit with their companions and remain calm before the show. Some audience members even chose to return to those spaces after the show to 'just chill' or have a drink and recall the fun they had just shared together.



One of the constant barriers to accessibility at venues was the lack of fully accessible toilet/changing facilities. The alternative was to change someone on a dirty toilet floor or, if they were too heavy to lift without a hoist, they would need to wait until they returned home. Ideally fully accessible facilities, called Changing Places would offer sufficient space for the disabled person and more than one carer to move comfortably, include an adult-sized, height-adjustable changing table, a powered hoist to transfer adult people between wheelchair and the changing table, showering facilities and a toilet with privacy screen. Such a 'toilet' would allow the adult with PMLD to have their personal care needs met and the carer an opportunity to use the toilet with dignity.

In an ideal world, café spaces with opportunities for wheelchairs to be accommodated and with access to blend café food (or somewhere to heat their own blended food) would enable more people to feel included, to feel welcome in the venue cafes, adding to the overall enjoyment of the theatre experience.

Standard 5: Communication

Extract...

Ensure staff are trained in appropriate total communication approaches to maximise expressive and receptive communication

PMLD Standards for Organisations - Standard 5: Communication (p24)

- Something to communicate (about)
- Someone to communicate with (communication partner)
- A means of communicating that is recognised and responded to by others
- Frequent opportunities to communicate (e.g. to take the lead or express preferences and interests) where communication partners are responsive and consistent

Frozen Light

This theatre company are meeting people with PMLD for the first time (possibly only time) during a one-hour theatre performance. It is beyond their capacity to have any in-depth knowledge about the unique and personal communication styles of each member of their audience. What they do have, however, is a very proactive and responsive stance. They use salient but generic augmentative and alternative communication (AAC) modes, coupled with interactive approaches.

Throughout *The Isle of Brimsker*, the performers draw on a combination of Makaton signs (a standardised system of sign language) accompanied by the spoken (or sung) word, using emphasised intonation, gestures, facial expressions and exaggerated postures. Their direct and indirect engagement with audience members is underpinned by appropriate communication techniques, such as the Intensive Interaction approach, to model and support the 'fundamentals of communication' process – turn-taking, eye contact, active listening, mirroring to reflect facial expression or postures in order to value and respect even the subtlest of unique, communicative attempts. In a similar style, the musician's personal serenades offer each person a very intimate and meaningful gesture to interact. Well-designed and perfectly executed special and sensory effects add further weight to the meaning and drama conveyed throughout the story. The benefit of these techniques for the audiences of people with PMLD are explored in greater depth in the previous reports on findings mapped to the PMLD Standards for Individuals.

- » Some invited expert reviewers offered Frozen Light some suggestions to further fine-tune their communication facilitation and support strategies:
- » Greater use of intentional pauses offers time for processing and reflection.
- » Consider using signs for core and key words only – so repetitions will strengthen focus and meaning.
- » Simplifying the narrative (in parts) will emphasise meaning of the key messages.
- » Actively use and incorporate the communicative responses offered by audience members.

One suggestion for organisations to support this standard is to evidence how they address and respond to the Five Good Communication Standards (RCSLT, 2013):

1. There is a detailed description of how best to communicate with individuals.
2. Services demonstrate how they support individuals with communication needs to be involved in decisions about their care and services.
3. Staff value and use competently the best approaches to communication with each individual they support.
4. Services create opportunities, relationships and environments that make individuals want to communicate.
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.

The personalised knowledge of individuals detailed here suggests people in support and enabling roles need to be appropriately informed and adequately skilled. They need knowledge about the process of communication and a clear grasp of the opportunities that promote and support its development. Their role as 'communication partners' is absolutely central and vital to an understanding of how best to support and enhance the communication of adults with PMLD. Support staff (and other carers, families included) need guidance and advice from specialist professionals - speech and language therapists and experienced trainers in this field - to be informed of some key pre-requisites that need to be embedded for successful communication (Doukas et al., 2017):

Supporting adults with PMLD

Previous reflections on evidence for Organisation Standard 3: Staff development (skills and confidence) shared observations of the diversity of professional practice by those in the support and enabling role. It is valuable to consider this area further here for the potential to gain further insight.

Organisations that advocate values-based recruitment processes will employ only personnel who genuinely want to be with people with PMLD. Similarly, they will maintain those strong values by providing adequate and appropriate training and supervision of their workforce. For this population, being appropriately skilled to empower and enable people with PMLD (using the right support at the right time) is NOT optional; it must be viewed as core and essential criteria for this role.

Whilst this evaluation gathered a wealth of evidence of positive, high quality, even exemplar practice around the skilled support offered to the audience members with PMLD, reflection on the less frequent occurrences of poor support practice holds great significance. There may be potential actions the Frozen Light Team can identify to improve or even transform the situation.

Observations by the reviewer and those reported on by the Frozen Light Team generally demonstrated a noticeable disparity between the skill sets of support workers from different public sectors. In the main, staff from school or college settings (where appropriate professional development is more substantial) were distinctly more highly skilled, attentive and responsive than carers from social care services, where opportunities for specialist training are known to be scant, and worker expectations of the people they support were conspicuously low.

As reported previously, the observed practice of some support workers from adult settings appeared 10, 20, 30 years behind that of many schools. This practice is very limiting and therefore impacts directly on the life experiences and potential skill levels of these (mostly older) adults with PMLD. Low expectations pervaded both partners – the paid carers had minimal expectations of the person they supported, and the adult with PMLD had low/no expectations of being able to have any sense of control or voice in their lives. In a number of extreme instances witnessed, individuals appeared to have no sense their communication reached anyone other than their own, internal selves; some were living in high states of anxiety, overwhelmed and fearful of what might happen next and not being supported to understand it when it did happen – others displayed compliance or simple 'acceptance', they had visibly given up trying completely.

This demonstration of poor-quality care is an incredibly tragic situation. It is a human rights issue and it is entirely preventable. No one wants or chooses to work in this way. However, the responsibility and accountability lie with providers, employers and service commissioners:

- » Training in the development of early communication and specialist communication approaches and techniques should be part of a core and essential induction for everyone working with individuals with PMLD.
- » All providers should routinely provide opportunities for specialist training for every member of their support worker workforce in order to gain appropriate skills for their role.
- » Every employee should have access to frequent, regular supervision from an appropriately-experienced line manager, where their practice and professional development needs are reviewed.

Unless the workforce are appropriately informed and effectively supported, they will be totally unaware there is a far more appropriate and positive way of working – one that leads to greater job satisfaction, improved morale and, of most importance, greater outcomes and improved quality of life for the adults with PMLD whom they support.

Within the context of Frozen Light performances, some simple actions could engender quick results. Frozen Light produce some pre-show literature, explaining the approaches used in their performances. This simple information gives an overview of what to expect and *outlines the companions role during the performance*.

Evidence from a range of sources shows this pre-show information was not always sent out with tickets by theatre venues. Informal conversations with audience members also highlighted that tickets were very often booked by other people (managers, office staff, etc), so they were unaware if the pre-show literature from Frozen Light had been received. Even if it had been, carers commonly said they had not seen or had time to read the information before coming to the show and so were uninformed of expectations (particularly that their involvement was key):

- » Frozen Light could revise their pre-show information adding greater emphasis to the crucial role of those supporting adults with PMLD.
- » Theatre venues need to explain the importance of this expectation and highlight this pre-show information when customers enquire and buy tickets.
- » Theatre venues must take greater care and accountability for sending out this pre-show literature.
- » Those purchasing tickets need to be aware of the expectations and role of companions and pass on this information and pre-show literature to those attending the performances.

Standard 6: Health and Wellbeing

Extract...

Effective support to promote the health and wellbeing of each person, including ... needs that increase the vulnerability of that person

PMLD Standards for Organisations - Standard 6: Health and Wellbeing (p25)

People with PMLD are wholly reliant on others to persistently monitor and actively support their overall health and wellbeing status. Earlier discussions highlight the increased risk and 'holistic vulnerability' experienced by this population due to the complex nature of the co-existence and inter-relationships between their multiple, disabling conditions (Doukas et al., 2017). Their very limited understanding of the world and great difficulties in communicating or controlling things around them, as an example, will impact directly on their emotional wellbeing and mental health.

Those tasked with caring and support need to be vigilant, to pre-empt (where possible) and actively support people with PMLD to manage situations that challenge them, to prevent escalation of anxiety and distress. This particular standard indicates that staff should receive high quality training in the physical and psychological health needs of the people they support. They should be skilled and informed, for example, in recognising and responding to indicators that a person may be in pain, discomfort or distress, or in supporting their emotional and mental health needs.

Postural care

Of significance to this discussion is the physical comfort of individuals with PMLD. Physical impairment is a common characteristic in the profile of needs of this group, impacting on their daily life to different degrees. Some individuals, especially those who are wheelchair users and those whose independent movement is limited, can be at risk of their body shape distorting without the right, active approach to postural care. Such deteriorating changes to body shape are preventable (and 'repairable'), but without appropriate management they can cause pressure ulcers, physical pain and greatly restrict bodily function - sometimes proving fatal. For this reason,

lack of appropriate postural care is recognised as a safeguarding issue.

One principle of postural care is aimed at supporting the body in symmetry, whilst recognising people still need to move or have alternative positions to access and engage in life. A very common issue experienced by this population is not having the right, personalised support equipment – seating or other equipment that is tailored to their very unique body and its very individual need. Austerity, funding cuts, lack of specialist professionals and equipment mean that all too often, people's bodies are not supported in the best way. They may have grown, their body shape may have changed, or they now need to wear a body brace or pressure garment meaning their current equipment no longer 'fits' or supports them in the right places. Lack of funds and overly long waiting times means people live with restricted access to the world, possibly in discomfort or pain and an increased risk to health – all of which detract from quality of life.

Discomfort let alone pain is at very least distracting but at worst totally absorbing if you are unable to tell someone about it or move independently. Your whole attention is focused on this internal sensation and your body's automatic response to it- perhaps tensing muscles, triggering a change of posture and even breath-holding. However amazing, awe-inspiring or motivating the world is around you, your interoceptive system will dominate and focus on that sensation. It is essential therefore that individuals with PMLD are physically comfortable; 'comfort for living' will enable them to engage in the world.

Sensory processing

Sensory processing disorder restricts a person's ability to regulate and integrate sensory information on a moment by moment basis. This condition has great influence on how individuals experience and perceive the world and how their internal emotional system responds to that constant challenge.

It is becoming increasingly recognised that many people with PMLD experience sensory processing difficulties (SPD), although its formal diagnosis in this population remains very uncommon (especially in the adult populations) due to lack of specialist professional assessment and advice.

You or I can filter information coming in simultaneously through all of our senses – either unconsciously (cutting out the whirr of the ceiling fan) or selectively (simply choosing to 'tune in' only to the conversation with our neighbour next to us). People who experience sensory processing difficulties can be over-sensitive or under-sensitive to certain sensory stimulation and sensations, making their bodies react in different ways. People who can articulate these sensitivities and differences give examples such as smell sensations that make them gag or the brightness of lights or certain frequencies of sound feeling physically painful.



Individuals whose early development is delayed likely experience the world primarily through their senses, but those delays and differences may add further to the confused messages to the brain. For example, if auditory awareness is still at a stage where it overlaps with other senses (like vision and tactile sensations), it can be doubly confusing – and again, possibly painful for some. In those with a lesser cognitive or physical impairment (perhaps those with autism), it can be common to see individuals cover their ears or hum to create their own white noise in response to uncomfortable auditory information in their environment.

We previously considered the importance of the interoception sensory system in ensuring 'comfort for living', but this sense has a broader impact. Interoception enables us to experience essential, internal feelings such as anxiety, fear, hunger, thirst, pain, body temperature, nausea, need for the bathroom, itching, fatigue. If you are unable to communicate those needs or get those needs met –they will automatically demand your sole focus. The urgency to use the bathroom (or needing to be changed) will distract you or override your interest in even the most motivating sensory experience in front of you.

Frozen Light

As discussed previously, this theatre company cannot expect to achieve every element indicated in these standards or evidence any element in great depth – simply because they are not directly supporting a constant group of adults with PMLD.

Despite being unable to genuinely personalise their work for each individual, Frozen Light do evidence many aspects of this standard however. Their proactive stance to ensure the comfort and wellbeing of their audience members is central to everything about their production – from the research and design stages through to their live performances in any one of the 53 UK theatre venues.

The pre-show guide gives key information about the unique Isle of Brimsker experience. The guide presents an overview of the story and what to expect, sharing information about the show, its duration, audience numbers and the space in which it takes place. This information is supported by clear images of the characters, the set and people having fun exploring some of the sensory props (frozenlighttheatre.com/resources/isle-brimsker-resources/) It offers a brief description about their approach using multi-sensory interactions:

- *'The actors will offer one-to-one interactions to the audience... These sensory interactions are an offer and no one has to engage if they don't want to.'*

The authentically relaxed nature of the performance is stated offering audience members to move around, make a noise or leave the auditorium as they want or need. It states ensuring people are not distressed but feel comfortable and at ease as a priority.

The guide gives clear direction for supporters:

- *'Carer/Companions - Your Role As a companion please get involved with the performance, assist the person you are accompanying but also feel and smell all the sensory items yourself, you will have a much better time if you do! Before the performance each audience member will be given a Visual Story. This is designed to reduce anxieties around the trip to the theatre. Could you please go through this with the person you are accompanying and bring it with you on the day.'*

A range of stakeholders and expert reviewers commented on the benefits of Frozen Light's approach and their performance to the wellbeing of individuals with PMLD in the audience (as previously reported). Some specifically alluded to the skills and techniques the Frozen Light Team used to address the wellbeing of their focus audience members:

- Q *[Individuals] ...' with PMLD have extremely limited options to meet themselves in stories and experience drama...involvement in the arts is good for ...mental wellbeing...'*
- Q *'Before the performance we could familiarise ourselves with the characters and what to expect with a Visual Story. This helps remove fear of unpredictability.'*
- Q *'...a curtain pulled around them cocooning them from other audience members – offering safety security. We were given blankets; essential oils filled the air ...gentle music. The actors gave clear, calm, secure instructions.'*
- Q *'Actors used their voices individually to talk to [the audience] and support staff – warm, smiling voices, supported with touch...Care needs were addressed throughout the performance supported sensitively by actors.'*

Frozen Light's attention to detail was evident and commented upon by audience members, reviewers and theatre staff. Thoughtful gestures like having ear defenders available for those who might find the music or singing a challenge, were clear indicators to their understanding of the wellbeing needs of their audience.

Theatre venues

We must acknowledge that theatre venues, in providing the context and setting for every performance, also make a strong contribution on the whole theatre experience, having a direct impact and clear influence on the personal experience for any

audience member. Whilst some views describe very positive 'offerings' and welcomes by some venues, the observations from across the whole range of stakeholders suggest there is room for improvement particularly when considering the needs of any audience member with additional needs, and people with PMLD in particular.

Previous discussions examined the physical environments of venues and their accommodations to meet the basic needs of their audiences. However, the health and wellbeing of some groups would really benefit from further considerations and reasonable adjustments (especially those with additional needs or disabilities – dementia, medical needs, physical and sensory impairments, mental health needs, etc):

- » Signage – staff verbally sharing information to visitors and visibly clearer signposting to available facilities is valuable.
- » Offering quiet places to wait or break out spaces as alternatives to busy thoroughfares, can help people to feel better.
- » Personal care needs – many people *beyond those with PMLD* need toilet and changing facilities that are more accessible – people with dementia, those who may have acquired brain injury through accidents and strokes, those who are unable to transfer themselves from wheelchair to toilet, people who need adult sized changing beds or space for two carers to assist them, people who need space and a clean, flat surface to manage colostomy bags and catheters, for example.
- » Audience members will be away from their home/base for 2-3 hours and may require a private place to administer medications or undertake medical interventions to maintain their wellbeing.
- » Some people would benefit from opportunities of having alternative seating or to come out of a wheelchair (e.g. relax in bean bags or space on the floor to move around after sitting for a long period).
- » Sensory sensitivities are very common; the hard architecture in venues can mean lighting is harsh and a common lack of sound softening furnishings can result in bold acoustics, with sound bouncing off the hard surfaces.

Often simple actions by venues, like improving the way information about amenities is shared, can really improve access and lead to better wellbeing outcomes for its entire audience. Such basic acts can go a long way to contributing positively on the widening participation agenda.

Standard 7: Social, Community and Family Life

Extract...

... create new opportunities for people and their families to form wider social relationships

Show commitment to promoting good quality social lives ... as well as active community participation and inclusion

PMLD Standards for Organisations - Standard 7: Social, Community and Family Life

Belonging or 'othering'?

Belonging, being part of and included in local social and community networks, is something most of us take for granted – a given that those opportunities are always available and it is our choice to opt in or out. People with PMLD we know have very different life experiences however (e.g. PMLD Network, 2008; Mansell, 2010; Harflett et al., 2015; Fergusson, 2016; Doukas et al., 2017). They continue to be pushed to the fringes of our modern society; not from choice, they are living on the margins of community acceptance with few opportunities, invitations or welcoming gestures to join in. The families and carers of this group by association also experience isolation similarly, often even within the communities or field of disability.

The strong ethos and values enshrined in this standard brings responsibility and accountability to every organisation providing public and community services and care. Each has a duty to actively address this right to human connection, to prevent social isolation, loneliness and ultimately poorer quality of life outcomes.

The role and value of the Arts is discussed to some degree earlier in this evaluation. The Arts creates an ideal context in and through which so many lives can be enriched, in particular adults with PMLD, their families and those who support and care for them.

We celebrate positive progress towards the arts in local communities becoming more inclusive through, for example, the growth of relaxed performance opportunities in theatres and cinemas. Evidence in the literature and through the media demonstrates valued community arts activities reaching wider groups - people with dementia, those in care homes for the elderly, the bereaved and others living with economic or social disadvantage (for example, MHF, 2011; All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017; Vandenbroucke & Meeks, 2019; Varvarigou et al., n.d.; Baxter & Low, 2017).

This evidence emphasises the huge benefits to those involved, their resilience and wellbeing; yet, as importantly, this also highlights the value and contributions those disenfranchised individuals, usually considered 'others' bring to our world (Powell, 2019).

Standard 4 for Individual describes evidence that is indicative of genuine participation and acceptance in social and community life:

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

Frozen Light

Providing access to meaningful theatre for adults with PMLD in their local community theatre venues is a central aim of the work of Frozen Light. It would be a far easier option to import their work into specialist settings – schools and day centres for example, where the audience base was readily available, the surroundings were familiar and skilled support staff were in-situ. In fact, this was advice given by two invited expert reviewers, whose expertise lay in working with children and young people with PMLD:

- Q *Good special schools ... are a really big resource for theatre companies like Frozen Light. ... [other specialist theatre companies] have recognised this and have made strong communicative links with schools. It is part of the secret of their success.*

However, performing to audiences in the heart of their own local community is an essential element of Frozen Light's goal. Their rationale is clear, that by raising the profile of this too often 'invisible' group, their local communities would begin to acknowledge their membership. With this greater presence, theatres and arts venues would respond constructively by ensuring they created appropriate opportunities on their programmes, opening the doors of these local amenities to the wider 'family' of their local community. Opportunities for a social life outside of their home, sharing in the mutual enjoyment of the theatre with family and friends should not be exclusively available to the non-disabled population.



Theatre venues

Some venues had made great efforts to ensure Frozen Light's performance was included in their recent programme. One programmer spoke about the two years in planning and financial negotiations she had undertaken to secure one date on this tour. She had seen Frozen Light perform at the Edinburgh Fringe and was determined she would bring it to one of the two theatres in the arts partnership where she was employed. Conversations revealed it was the added capacity of two theatres working collaboratively that had enabled the smaller town venue to gain financial underpinning for the two shows on that date to be brought to an area (for people with PMLD certainly) that was otherwise culturally barren. Of note here is that of the audience members of the two shows at this venue only two were adults with PMLD (places for 12 adults with PMLD in total), as other tickets were potentially 'mis-sold'. One show was sold out to a special school who travelled for an hour to see the show (frequent visitors to Frozen Light performances) but these were more-able students (not with profound and multiple learning disabilities); the second show was attended by two individuals with PMLD who lived in the area (but had never visited the theatre) and four vulnerable adults from a local drop-in for people with mental health difficulties (also a first visit to a theatre for their whole group).

This venue, like many others new to this area of arts provision, demonstrated there is still considerable ground to cover to widen involvement in the theatre community – for example:

- » finding and reaching people with PMLD in the locality (and beyond)
- » establishing an audience-base of people with PMLD for future shows

- » marketing (targeted and mainstream) of opportunities for adults with PMLD
- » developing and establishing a more inclusive programme
- » gaining a 'reputation' for this inclusive programme
- » looking for collaborative links and partnerships to gain access to the necessary funding opportunities- particularly in the early stages

Members of the Frozen Light Team frequently shared their views on the role of theatre venues to widening participation in community life;

- Q *We are (FL) ... aware of huge leap from previous shows in developing what we do and how - based on the audiences we meet - and the venues – now the [focus] is on them*
- Q *[as venues] become more well known for this and people [with PMLD] more visible in society – this will encourage venues to reach out more to them, to cater specifically for them*
- Q *They will be offering something unavailable - to people who need it most.*
- Q *Enjoyment is not a luxury!*

One expert reviewer added to this perspective:

The chance to go to the theatre is not a frivolity of life, it is an opportunity to have life enriched, to develop and connect. People with PMLD of all ages are notoriously socially isolated, the chance to be included in theatre is joyful for them and restorative to those who care for them who also suffer the burden of that social exclusion.

(Sensory Engagement & Inclusion specialist)

6. Concluding Remarks & Ideas for Consideration

A PART OF society, not APART FROM it

The Isle of Brimsker, a performance toured by Frozen Light to 53 venues across the UK, was audited against the PMLD Standards (Doukas et al., 2017). This framework is a set of benchmarks and a quality assurance tool to assess the work of those delivering any form of service or provision for people with profound and multiple learning disabilities (PMLD). The review process considered the complete set of core and essential service standards within this framework to examine the experiences of adults with PMLD, their companions and other stakeholders involved in their theatre visits.

Without question, the findings of this review ascertained a wealth of high quality indicators to evidence achievement against every standard; those for individuals with PMLD and those for organisations. The evidence collated and analysed throughout the process demonstrated these positive accomplishments reflected views across every stakeholder group. Audience feedback was overwhelmingly positive and, even when pushed, those attending the performances found it difficult to offer ideas and areas for improvement.

A principal outcome of this investigation was to recognise and applaud the strong ethos and values of Frozen Light in all aspects of their work. Respect and positive regard for people with PMLD is embedded, whether it be through their pre-show guidance, their supportive preparation and briefings for theatre venues, or their direct, face to face interaction with individuals in their audiences.

Frozen Light:

- respect and appreciate each individual for who they are
- value people's unique communication styles
- listen and respond with sensitivity

- ensure access is personalised and appropriate
- create opportunities to have a voice, state preferences, take the lead and have a sense of control
- offer diverse approaches of support
- empower and enable their audience
- utilise interactive, immersive and responsive approaches to offer meaningful structure and cues, sensory and musical engagement and shared enjoyment
- offer powerful narratives taking people beyond their familiar experiences

Everything they offer is presented through a positive image of people with PMLD.

They:

- inspire others by role modelling outstanding practice and support
- present high quality theatre, equal to any main-stream offering
- balance risk with security to support their audiences
- challenge the concept of inclusive theatre
- take 'relaxed performances' to new levels
- encourage others to be creative in their own practice

This evaluation must acknowledge the significance and potential influence of this small theatre company's work beyond that of *simple entertainment* (not meant to be patronising).

The overall review findings, when considered together with the lived experiences of adults with PMLD and the wider context of their lives, valuably highlighted a number of shortcomings. These include issues around attitudes towards them and their status within society, the inequity of access and opportunities afforded to them, and the compounded impact of these factors on the quality of their lives. Frozen Light clearly demonstrate relevant expertise, experience and innovation to positively further and redress this obvious imbalance.

Ideas to seed future developments

In response to the ongoing discussions within this evaluation, two broad themes arise for consideration:

- i. The value of Frozen Light's theatrical performance work and their role in influencing wider change;
- ii. The role of 'others': theatre venues, those supporting people with PMLD and communities (in the widest sense).

The potential role of Frozen Light

Every performance created by Frozen Light to date has successfully offered enjoyable, meaningful and empowering opportunities for people with PMLD themselves. These opportunities lead to improved outcomes, influence skill development and engender a sense of voice for their audience members.

They should consider greater involvement of people with PMLD as 'experts by experience' to enhance the relevance of their work by, for example audiences with PMLD could support in:

- developing an advisory/reference group – to help prioritise and shape areas for future development,
- piloting new work
- being reviewers of venues
- being reviewers of performances
- By disseminating these actions and outcomes, people with PMLD could be agents of change in tackling prejudice and negative attitudes and, importantly, challenge inaccurate assumptions and raise the expectations of others.

Share innovative models of working, training and inspire good practice

The scope for this development is potentially vast. There are so few professionals who are knowledgeable and skilled at working with and engaging adults with PMLD, and fewer still with experience and expertise in creative performance arts. Their skill set and experience has value and appeal to a diverse audience, for example:

- theatre venues & their entire staff teams
- support staff
- families
- Learning Disability care providers
- Learning Disability specialist professionals (SALT, Social Workers etc)
- policy makers (e.g. APPG working group)
- arts peers – inclusive theatre and others
- the arts more generally
- members of other 'communities' (people with dementia, local amateur dramatics, groups offering support for vulnerable people, etc)
- students – the future
- professionals, policy makers and future agents of change

Guidance - for companions, observers and reviewers

Develop simple suggestions for those accompanying people with PMLD to the theatre to get the most from their visit to the show. Clarify what the 'right support' might look like – approaches to enhance engagement, support communication and to encourage participation. Offer some more practical and less invasive ideas to capture evidence from shows, as alternatives to the distractions and interruptions of taking video and photos.

A simple suggestion could be a user-friendly recording sheet based on the **PARTY prompt** (Fergusson & Brookes, 2015). The memorable acronym 'PARTY' is a simple prompt to focus your observations skills so as to capture the most significant things that happened 'in the moment', during the performance (pre/post-show too). It helps the supporter to acknowledge, for example, responses and actions that may be new, unexpectedly repeated or used more confidently. These observations can be valuable to help understand what it is that prompted the individual to be successful (or not).

The letters of the acronym have no prescriptive list to follow; they are rather simply an easy way to identify what is most worthwhile to record. For example, it could prompt you to consider the importance or influence of:

P – people, place, position (could be position of person with PMLD, the performer or where resources are presented)

A – access, activity (what was happening at the time), arousal state (sleepy, alert, anxious), attention and concentration span (what were they focused on and for how long)

R – responses; what did they actually do? anything new or done in a different way? did they repeat it? perseverance of responding or level of engagement

T – (time-related): time of day, duration of attention/engagement, sequence of events e.g. when the lights came on, following the water spray, after a seizure

Y – YOU: what was your role? what did you do? how did you offer support? what worked?

This simple record could also offer potential support and guidance for novice theatre staff who are often asked to comment on a Frozen Light performance. It would support their understanding of how to more accurately and meaningfully judge engagement and satisfaction from audiences with PMLD.

Frozen Light could also valuably draw on this PARTY prompt tool themselves when, for example, developing and trialling new work with people with PMLD as their 'experts by experience reviewers'.

Raised profile and place - shaping for people with PMLD

The work and influence of Frozen Light can shine a spotlight on this overlooked population, influencing direct change as a consequence. For example:

- highlighting the needs of this population at local and national levels through direct performances and via dissemination
- supporting local services (public sector and other organisations) to identify this population people – discover who they are and where they are (local authorities really don't know this)
- supporting theatre venues to develop their audience base of people with PMLD
- evidence of local/national need will identify demand for increased opportunities
- a raised profile will raise the needs for fully accessible, local facilities in venues and public amenities (e.g. Changing Places as a minimum)
- 'inclusive' and 'relaxed' performance opportunities explored further in light of this need
- many other unexpected spin-off opportunities

This area presents opportunities to respond through diverse routes. However, Frozen Light must include public dissemination as a future action. There is a dearth of relevant literature and resources specific to the needs of adults with PMLD.

Potential of Frozen Light's own theatrical work e.g.

- Continue to develop new, high-quality accessible theatre and other arts/cultural activity appropriate to audiences of adults with PMLD
- Previous work
- tour previous work again – rotate shows to develop a fuller programme at venues, also offering variety and familiarity
- use previous work to train others – interns, apprenticeships or secondments (paid by other groups?)
- offer previous work to other theatre companies who will (also) tour it ... perhaps franchise?
- increased access to the (what were they focused on) performances will create opportunities every year/season
- New opportunities: based on new and previous work
- Offer simplified drama activities or 'Frozen Light stories' as resources for sale. People with PMLD:

- can enjoy these familiar narratives in between tours (think young children repeatedly watching Frozen?)
- can familiarise themselves and prepare for the next tour
- will have a meaningful focus to create opportunities to do things with other people

New developments in and by theatre venues

There is valuable potential for local theatre venues to become hubs to develop a greater community presence for adults with PMLD. They would become familiar and comfortable from visiting the venue regularly. It would be the chance to promote a sense of belonging, membership of a group as citizenship in action.

Such an idea could maximise the use of 'empty' and unused spaces during the daytime, when utilised as a venue/base to:

- Using Frozen Light resources, facilitate (or offer potential to others) for regular group activities (sensory storytelling, drama clubs, etc).
- Expand the activities to involve other local artists and other art forms – thus creating even more opportunities.
- Raise the profile and reputation of the venue as being inclusive, which in turn would expand the audience base further.
- PMLD groups develop their own new work.
- Produce performances of their own to an invited audience.

Collaboration

Creating partnerships with others builds greater potential and opportunities for economies of scale. This population of people with PMLD will always be a minority; broad estimates suggest there are approx. 36,000 children and adults across the UK. This increased capacity can respond to a great diversity of actions and needs:

- People with PMLD all need appropriate opportunities to do meaningful things with other people; joining forces with others can maximise those opportunities.
- Communities (in the very widest sense) need awareness raising about people with PMLD and how to meaningfully include them.
- Working together generates the chance to share and pool e.g.

- Expertise
- Funding – e.g. off-set costs by mainstream work,
- larger organisations work with smaller venues
- accessible spaces
- resources
- manpower
- audience bases
- People with PMLD may be willing to pool their budgets to fund things they can do together – if the opportunities are there.
- Engage local groups, take different roles to get involved – theatre and other arts groups could be the storytellers & facilitate activities, and recruit volunteers and befrienders.

These ideas are merely the start of a collection of ideas to seed and grow much needed change. Such developments would directly impact on the lives, the wellbeing and the social status of people with PMLD. The PMLD Standards were developed to drive change and improvements such as these.

The expressed goal of Frozen Light is to challenge others, to keep raising the bar and aim for higher quality outcomes for adults with PMLD. Their bar is firmly set on people with profound and multiple learning disabilities being 'a part of society, not apart from it'. This evaluation so evidently highlights that the work of Frozen Light can lead the way for this transformation by raising the bar on inclusive theatre for people with profound and multiple learning disabilities



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Evaluation of The Isle of Brimsker by Frozen Light

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